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[COMMITTEE PRINT]

SHARING THE CARING: OPTIONS FOR THE 90s AND BEYOND

A POLICY FORUM

BY THE

SUBCOMMITTEE ON HUMAN SERVICES

OF THE

SELECT COMMITTEE ON AGING
HOUSE OF REPRESENTATIVES

ONE HUNDRED FIRST CONGRESS

SECOND SESSION

MARCH 1990

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FOREWORD

HONORABLE OLYMPIA J. SNOWE
RANKING MINORITY MEMBER
SUBCOMMITTEE ON HUMAN SERVICES
SELECT COMMITTEE ON AGING

Since 1986, Senator Glenn and I have sponsored legislation that has established the week of Thanksgiving as National Family Caregivers Week. For the past three years, the outpouring of support for this legislation from national organizations has resulted in a policy forum on elder care. The 1989 forum, "Sharing the Caring: Options for the 90s and Beyond" focused on innovative and collaborative programs being implemented by businesses and both public and private agencies.

This Subcommittee publication is an outgrowth of the 1989 elder care forum. It includes initiatives of the business community, a research overview and available options to address the problem.

As we look toward the 21st century, the tremendous burdens of caregiving will become even more acute. The population is aging. The "old-old", those over 85, is the most rapidly growing age group. These individuals are the frailest of the elderly, less independent, and most in need of care.

Family caregivers -- typically wives, daughters, and daughters-in-law -- are the principal providers in our long-term care system. Even though women are increasingly moving into the work force, they are not decreasing their role in providing care to elder family members.

Recently, the corporate world has begun to address the elder care issue. Businesses are becoming acutely aware of the negative impact family, and informal, caregiving has on the work place. As such, they are addressing the issue with a variety of programs. In many cases businesses are forming collaborations with public and/or private agencies to provide support services to their employees that are caregivers. In particular, I would like to commend the Administration on Aging and the Washington Business Group on Health for their innovative "Partnership in Aging" program which promotes collaborative public/private efforts to address aging related issues in the work place.

I wish to thank the many organizations and individuals who assisted with the forum on "Sharing the Caring: Options for the 90s and Beyond" and this corresponding committee print. I would also like to recognize all of the committed elder care providers who play a significant role in meeting the needs of our elder family members.

REMARKS OF SENATOR JOHN GLENN
POLICY FORUM ON ELDER CARE
Tuesday, November 14, 1989

It is a pleasure to once again join Congresswoman Olympia Snowe in sponsoring this Policy Forum on Elder Care. I am pleased to welcome all of you to "Sharing the Caring: Options for the 90s and Beyond." Meeting the challenges presented by our rapidly increasing elderly population requires that all of us -- from government, the private and voluntary sectors, and individuals -- work together.

The issue of elder care is important today and will be even more critical in the future due to our aging population and the increasing number of women who are working outside the home. The fastest growing segment of our population is the age 85 and older group, the group most likely to suffer multiple chronic ailments, thus requiring the assistance of caregivers. Women, who are the traditional caregivers in our society, are increasingly entering the labor force. Already, a majority of all caregivers are employed.

Caregivers often face stressful situations in attempting to balance the demands of their jobs, their families and their caregiving responsibilities. It is estimated that at least one-third of employed caregivers lose time from work as a result of their caregiving duties. Many caregivers are forced to sacrifice employment opportunities to provide care, thus jeopardizing their own current and future economic status.

Many businesses are recognizing the importance of assisting employees and retirees with their caregiving responsibilities. Public and private agencies are implementing innovative community programs utilizing both volunteers and paid staff. These projects frequently are collaborative efforts between business, government and private human service agencies. Today's forum is intended to provide information about these programs and about the services that are needed to assist family caregivers today and in the future.

Family caregivers play a vital role in our society by providing over 80 percent of the care given to the elderly. Without assistance, such as respite care, training, support groups and flexibility in the workplace, caregivers may suffer from severe stress. Without help for family caregivers, the only alternative for the elderly may be a nursing home. By helping prevent caregiver "burnout," we enable families to continue caring for their elderly members.

Because Americans are living longer, more and more of us will find ourselves responsible for the care of an elderly loved one. I would like to thank today's speakers, and all of you who are in attendance, for your efforts to highlight the contributions of family caregivers, to increase awareness of their needs, and to work together to meet the challenges of our aging society today and in the 21st century.

FOREWORD BY THE HONORABLE THOMAS J. DOWNEY
for
THE BRIEFING, "SHARING THE CARING:
OPTIONS FOR THE 90'S AND BEYOND"
NOVEMBER 14, 1989

As the Chairman of the Subcommittee on Human Services of the House Select Committee on Aging, I commend the Ranking Minority Member of the Subcommittee, Congresswoman Olympia Snowe, and Senator John Glenn, of the Senate Special Committee on Aging, for presenting this briefing on "Sharing the Caring: Options for the 90's and Beyond." This briefing is one of a continuing series of educational forums held by the Subcommittee on the important issues of providing human services to our Nation's elderly population.

Recent estimates indicate that more than twelve million older Americans have some form of limitation in their daily activities because of a chronic condition. Approximately five million of these people need help in one or more basic physical activities or require assistance in managing domestic activities. At the present time, there are over two million Americans who act as caregivers, providing help to elderly family members residing in the community. Without these caregivers that quality of life for millions of older Americans would deteriorate immeasurably.

As we approach the end of the twentieth century, the number of elderly Americans requiring assistance is bound to increase as the number of Americans over the age of 75 grows. Complicating the situation is the changing nature of the American work force as more and more women pursue full time careers. Women, who have traditionally been the primary caregivers for their elderly relatives, face greater stress as they try to balance the competing claims on their time and energy. Clearly we need to find a better solution to the growing needs of older Americans and their caregivers.

This briefing helps us to focus our attention on the problem and on those dedicated people in the public and the private sector who are forging a new path in the search for an effective and humane solution to the difficult, and complex problems facing caregivers. We owe them our gratitude and our best effort to assist them in their labor of love.

Administration on Aging

November 14, 1989

Dear Colleague:

The Administration on Aging is pleased to be a supporter and participant in this forum on caregiving and the elderly. Today, families are the primary national resource available to older persons. Caring for vulnerable older relatives is a traditional American value that should be maintained and encouraged. Preservation of the family as an institution is ever important as our society grows older and we look toward the challenges of the 21st century.

Most older persons are healthy and independent; however, as our society ages, more of our older relatives will require care and assistance from others. Increasing numbers of family caregivers are also employees whose dual roles present major implications for a business, its productivity and success. We are beginning to recognize that the burden of these multiple responsibilities can compromise the caregiver's health and the ability to be an effective and productive employee and family member. It is certain that as our population grows older and lives longer, the phenomena of the employed caregiver will become more and more prevalent.

We as citizens, public servants, private sector employees and family members, must all work together to create institutions and practices that effectively respond to the aging of American society. As part of this commitment, we must assure that caregivers have the support and assistance they need to maximize their potential both as employees and family members. The Administration on Aging and its network of 57 State Agencies on Aging, 670 local Area Agencies on Aging and over 27,000 local service providers look forward to new opportunities for cooperation to accomplish this goal.

Sincerely,

Joyce T. Berry

Joyce T. Berry, Ph.D.
Acting Commissioner on Aging

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SECTION I

WHO CARES FOR THE CAREGIVER?
by
Lou Glasse, President
Older Women's League

Senator Glenn and Congresswoman Snowe are to be commended for recognizing our nation's caregivers and their selfless generosity. By creating a National Caregivers Week, Senator Glenn and Congresswoman Snowe have focused attention on seven million Americans who give of themselves to care for aging and disabled relatives, oftentimes twenty-four hours a day, 7 days a week, for months--even years. Establishing a National Caregiver's Week has brought us this forum and stimulated local groups to honor and to consider the needs of caregivers. This is an important first step in developing a national program of care for those who are disabled or chronically ill.

The second step must be taken by us. We must debate what should be the responsibility of families, community, employers and the government.

I would like to begin by asking you some questions. Would you reply by raising your hand?

1. How many of you have parents or parents-in-law who are living?

2. How many of you have older siblings who are living?

3. How many of you expect that when you are 65 years of age you will live with a spouse or house-mate?

Most everyone in this audience has raised his or her hand in answer to at least one of these questions. Here are other questions:

4. How many of you are now or have been a caregiver within the past year? Within the past 5 years?

5. How many of you anticipate that you will be a caregiver for a relative or friend within the next 10 years?

Again, the majority of you have raised your hands.

6. How many of you have long-term-care insurance coverage?

Only a handful of you have such insurance coverage.

7. Of those who have long-term care insurance, how many of you have a policy that provides extended home and community care if you should become frail or have a disabling and chronic condition?

Of approximately 250 people in this audience, only three people responded affirmatively.

To summarize: The great majority of you have family who may need a caregiver and you anticipate that you will be a caregiver. Many of you already have been a caregiver--some for an extended period of time. In addition, many of you may expect that you, yourself, will need a caregiver. Despite this knowledge, only a few of you have any long-term care insurance, and fewer still have insurance that would provide much care within the home. Unfortunately, this caregiving gap is reflected in the rest of society.

Family caregivers are the foundation of health care in America. For most Americans, it is our families who nurture and nurse us from birth to death. But this house of health care is reinforced with physician, clinic and hospital services when acute illness strikes. Regrettably, thirty-seven million citizens, who are not protected by health insurance coverage, have very limited access to doctors and hospital care. They must depend almost entirely on their families.

This is also true for the physically and mentally disabled--those in need of long term care. For them, family caregivers provide virtually all services. They are the unpaid nurses, advocates, aides, homemakers, maintenance workers, cooks, drivers, care managers, and financial managers. They even provide financial support.

Who are the caregivers? Women are. Though men are assuming greater caregiving and parenting responsibilities than in the past, the paid and unpaid caregivers of the young and the old are overwhelmingly women---principally wives, daughters, and daughters-in-law.

Of the approximately 7 million Americans who need long term care, three out of every four persons are cared for at home by families and friends. Without this attendance, assistance and nursing that caregivers devote to the disabled, particularly the elderly, our hospitals and skilled nursing facilities would be flooded. The enormous cost of this care would shift to federal and state budgets.

But caregiving is costly for families too. Many families adjust their work schedules--in the 1982 Long-term Care Survey of informal caregivers, 11% quit work. Other surveys report that up to 28 percent quit jobs to be caregivers. In addition, approximately 2 out of 10 worked fewer hours or took time off without pay. Almost 3 out of 10 changed their work schedule.

This reduction in paid employment is a principal cause of women's lower wages, lower pension earnings, lower social security

benefits and their higher health care costs. Thus, caregiving is a cause of the high percentage of older women who are impoverished.

Caregivers adjust their social and marital relationships, their leisure time, indeed their lives, to provide succor to aged relatives. And more family caregivers are doing just that--lovingly, willingly, regardless of the cost to themselves.

For many, this time of taking care of a loved one is a treasured time of sharing, a time to express love through tenderness, patience and understanding. But it can also be the backbreaking work of lifting, bending, turning and cleaning soiled bed clothes and linens. Or the heartbreaking experience of watching a loved one deteriorate.

For many, this strengthens and deepens the commitment of the caregiver and the cared-for to each other, and it provides lasting memories. For some it is a time of pain, struggle, and exhaustion that may stretch to a breaking point their capacity to care. We know that some older persons are abused when their burden becomes too great. From time to time, news articles report the killing of an ailing spouse and the suicide of the relative who killed.

What else do we know about caregivers?

We know that over one-third of the caregivers are over 65 years of age, and 10% are over age 75. The average caregiver is 45 years of age.

Two out of three are married and must struggle with other family responsibilities. Almost two million are "women in the middle," who care for growing children while simultaneously providing care for on older relative.

The single caregiver has a different problem. This unmarried child may suffer from isolation, and depression. She/he may alter social life and delay or cancel marriage plans.

And one out of every five caregivers has been providing care for five years or more. The Older Women's League recently heard from a 70 year old woman who was caring for her 101 year old mother and had been doing so for 20 years. She pleaded, "what I need most is one night of unbroken sleep."

After hearing such stories, we must decide which path to take. Our nation is at a crossroads. Can we continue to depend solely on family and friends to care for the increasing number of persons needing long term care? Should we close our eyes to the enormous cost to the caregiver and the effect on the care-receiver? Or should we build a new highway that provides all Americans with equal access to health and long term care?

We know the path we have been following is difficult to penetrate, with barriers of cost, regulation, and red-tape that impede access to in-home and community services and respite for the caregiver.

We know there are worn ruts of medical, hospital and funding procedures that stifle good discharge planning and outpatient care. We know there are gaps in services that can threaten the health of the patient. We know that some elderly stumble down the path alone. Some--we don't know how many--never reach the safety of renewed good health.

Also, we know that few will be able to personally afford the long term care highway to trained caregivers, modern technology, experienced staff, and freedom from fear of the high cost of extended care. But our government is afraid to discover the size of the need.

And so we hesitate. We seem more willing to let families go bankrupt and caregivers to risk their own physical, mental and financial futures than to develop a national plan to protect all age groups from the devastating burden of long term care.

Our mission must be the enactment of national long term care insurance that provides socially oriented in-home, community and nursing home care.

Our first priority should be to secure respite--i.e. relief for the struggling caregiver.

But we cannot do this adequately with our current, haphazard system of reimbursement for paid caregivers. Wages, benefits and working conditions are so bad that the turnover rate for nursing home aides is 70-100% each year. For home care aides, the rate is 60%, with 80-90% leaving within two years. Their average, hourly wage is $4-$4.50. Similiar conditions surely exist for workers in adult day care programs. When personal care aides are untrained, underpaid and poorly supervised, the family cannot be confident of quality care.

WHAT SHOULD BE DONE? The Older Women's League recommends the following:

1. Our Social Security system should be changed so that America's unpaid caregivrs are not penalized. Either Social Security credit should be given for years of caregiving or those years should not be counted in determining benefits. Perhaps we should adopt Great Britain's example: there, men and women are credited with up to twenty Social Security years if the homemaking spouse also cared for a child or an aged, sick or disabled relative.

2. Employees, who must drop out of the labor force because of caregiving needs of the aged, should not be forced to forfeit their health insurance and disability coverage. Such persons are already making great financial sacrifices. They should not, also, have to sacrifice their own health.

3. Legislation, such as Family and Medical Leave Act, should be enacted to allow family members a temporary, unpaid leave to arrange adequate care for chronically ill children, parents and spouse. Current proposals, regrettably, omit spouses. I hope Congress won't make the mistake of cutting off one part of the family in a Family and Medical Leave Act.

The public has pushed for this intergenerational legislation. I understand legislator's concerns that employers might object to broadening the coverage in the bill, but I question the wisdom of segmenting the family protection. Society would be truly outraged if husbands or wives turned their backs on the caregiving needs of a spouse. Then, surely, we shall be outraged if government provisions stop short of supporting the caregiving needs of the spouse.

Some courageous and responsible employers such as Travelers Insurance, International Business Machines Corporation and Stride Rite Corporation are already helping their employees carry this family burden. Other corporations should be encouraged to assist employees to handle family needs.

4. We must improve the working conditions for paid caregivers. Public and private insurance reimbursement should support a living wage and provide conditions that encourage competence and satisfaction among those who bathe, feed, dress and care for the disabled and chronically ill.

Finally, families must do a better job of preparing for the long term care needs of its members. Responsibility for caregiving should be shared between husbands and wives, sons and daughters, between men and women. Employed family members should plan with their employers for family caregiving needs. And we must all press for national, long term care legislation that provides respite, in-home, community and nursing home care. As our society gets older, each and everyone of us may both need a caregiver and be a caregiver.

Thank you.

Family Caregivers: Issues and Challenges in The 1990s

As the 20th Century ushers in its last decade, public health issues for family caregivers in America are attracting national attention. Demographics, longevity, and social change, together, have created historically new sociocultural challenges for families. By the end of the 1980s there were more people 65 and older in the United States than the entire population of Canada--a nation of older adults within a nation, so to speak. Moreover, the over age 85 (the "old-old") represent the fastest growing part of the population as a whole. By the middle of the next century there will be as many people 85 and older in the U.S. as the entire population of Australia around 1990; everyone who will be 85 in the mid-21st Century is alive today. Added to the combined impact of commanding demographics and increasing longevity is one of the most dramatic illustrations of historical change in family structure. That is, the finding that for the old-old, the children providing their care are often themselves senior citizens. This colors expectations that society should/can have toward these older adult caregivers.

In fact, one-third of those who care for frail relatives are themselves

over the age of 65. A further new phenomenon is emerging. There are increasing reports of older adults continuing in the caregiving role into advanced old age--situations of the old-old caring for the young-old. In short, the configurations of family caregiving relationships have become more numerous and complex, resulting in greater opportunity for strain in the family system. Another example is the situation of "women in the middle"--women caught between the demands of bringing up their children and bearing the burden of caring for a frail parent. Such is compounded when the woman is working, worse yet when she is divorced. Seventy percent of caregivers of older adults are women.

Research on the family is critical in helping us better understand risk factors for stress on the one hand and strategies for more effective coping on the other hand. For example, studies show that while the bulk of caregiving burden is assumed by daughters, there is some good news about sons. It has been shown that in the absence of daughters, sons organize effectively to care for elders. When a family includes adult sons and daughters, it is often the adult child geographically closest to the parent who assumes caregiving. There also tend to be differences in the nature of caregiving in comparing sons to daughters. Sons' caregiving is more likely

to be "instrumental" in nature, such as with financial assistance and home repair; daughters are more likely to perform personal care and housework. Of growing concern is the number of both sons and daughters who report quitting jobs or taking extended leaves of absence because of caregiving responsibilities--the case with five percent of sons and twelve percent of daughters. Understanding family caregiving issues and options becomes yet more involved when minority and ethnic factors are considered, both the subject of expanding research initiatives.

Of additional concern is growing awareness of an enormous and significantly underappreciated public health problem among family caregivers--the impact of caregiver stress on caregiver health. The adverse impact of emotional strain on physical well-being among older caregivers is a public health sleeper. To begin with, the frequency of depressive symptomatology among caregiving relatives of older adults with chronic illnesses is disturbingly high. Depending on the study, from 25 to 80 percent of these relatives develop clinically significant symptoms of depression during the course of caregiving. This is especially true with Alzheimer's disease. Beyond this emotional strain, however, are findings of compromised functioning of the caregiver's

immune system, resulting in increased risk for infection and slowed healing following injury. Again, studies of caregivers of Alzheimer patients stand out in this regard.

There are approximately one and a half million people in this country over the age of 65 who live with another person because of physical or mental limitations and require the assistance of that other person. While dementia is the most common problem here, other problems produce related demands. These include strokes, mobility limitations (due to falls, fractures, osteoporosis, and osteoarthritis), and urinary incontinence.

In addition to research on better understanding the problems that caregivers experience and the coping strategies that they employ, studies focus as well on the role of a number of services and service providers to whom families can turn for assistance. These include meals on wheels, volunteers (e.g., for transportation), homemakers, visiting nurse services, adult day centers, innovations in the workplace to assist working caregivers of frail elders, respite services, assisted living arrangements, and nursing homes, among many others.

At the same time, the availability of a service does not always assure its utilization. Hence, services research focuses on both service design

and service delivery. Consider the frail older person who is very much in need of homemaker assistance, but insists, "I don't need any help!" Family systems research has shown that often an effective strategy is to identify the relative or friend to whom the one in need best relates to and have that person help to advise and gain the cooperation of the elder. Mental health problems on the part of the older person can also interfere with caregiving, creating significant anguish on the part of the caregiver. For example, in the case of Alzheimer patients who also develop delusions, the family caregiver can experience the phenomenon of triple jeopardy. At one level, the caregiver is already experiencing significant emotional stress in observing devastating changes due to dementia in a loved one; at the second level there is the physical and financial burden of providing care; at the third level (e.g., in dealing with delusions), the delusional patient may manifest accusatory or hostile behavior toward the caregiver. Hence, on top of emotional and physical burden (double jeopardy), a third element of hostility (rather than appreciation) enters to overwhelm them. But delusions can be treated, and, in the process, patient coping improves, caregiver burden diminishes, and family equilibrium returns.

Given all of the above, a paraphrase of an old admonition puts things

into perspective: "For every complicated problem, there is a simple solution. And that simple solution always fails." Family caregiving issues for older adults in the late 20th Century comprise a complicated scenario that is not likely to respond to a simple solution. What is needed are creative, innovative approaches--products of imaginative scientific research and enlightened social policy.

11/13/89

REMARKS of SARAH F. MULLADY, DIRECTOR
EMPLOYEE ASSISTANCE PROGRAM, CHAMPION INTERNATIONAL CORPORATION
BEFORE POLICY FORUM on
ELDER CARE "SHARING THE CARING: OPTIONS FOR THE 90's AND BEYOND"
PRESENTED BY
SENATOR JOHN GLENN AND CONGRESSWOMAN OLYMPIA J. SNOWE
November 14, 1989

Champion International Corporation, a Fortune 100 Company, almost 100 years old and one of the world's leaders in producing forest products, with operations in almost every state, Canada and Brazil, is very honored to be part of this panel today.

Accompanying me today, is Elaine Hohman, Regional Employee Assistance Program Coordinator, based at our Hamilton, Ohio paper mill -- the original home of Champion. Elaine also has EAP responsibilities for other Champion operations in Ohio. With me also is Dana Mosher, Regional Employee Assistance Program Coordinator based at Champion's Bucksport, Maine paper mill, with EAP responsibilities for all operations in Maine, including our sawmill in Costigan, and Timberland's personnel.

Joining with us is Mr. Donald Bowden, Chairperson of Champion's Maine Retired Employee Assistance Program (REAP), a retiree since 1981.

Champion is delighted to join with the Washington Business Group on Health in Saluting National Caregiver's Week, November 19-25th, which is being publicized through the National Family Caregivers' poster.

Champion's Employee Assistance Program began in February 1981. Designing the program from years of experience in the Employee Benefits function, as well as my personal experience as an only child and a caregiver to both deceased parents, two maiden aunts, and currently the long distance caregiver of a widowed aunt living in another state, I knew that all employees, male and female, could have performance and attendance negatively impacted. Thus the employer's profitability can ultimately, be negatively impacted by caregiving.

From the onset in 1981, Champion's EAP provided three visits to a licensed psychologist or psychiatrist at no cost to the employee to get help outside the Champion Benefits Program with problems relating to being a caregiver to elderly parents and/or other dependents.

For our over 21,000 employees in the United States and our 20,000 retirees, Champion understands that caregiving is still the role assumed predominantly by the female. However, today it is also a male employee problem -- influenced by many factors -- the mobile society - people separated geographically from aging parents, or other dependents, single parent homes, the need and the right of women to have distinct careers outside the home, the lack of sufficient and varied facilities to care for the elderly, the cost of both inpatient and outpatient treatment and the lack of understanding on the part of many men and women of the present medical caregiving system, as well as the scarcity of medical professionals trained in all aspects of caring for the elderly. My experience with the negative impact on job performance of caring for the elderly is very personal.

I joined Champion in January 1977, with many years in the Benefits function of two other major employers. I received promotions and annual performance reviews indicating the highest ratings attainable in Champion.

In 1981, with the creation of the Employee Assistance Program, I was appointed its Manager with the mandate to design and implement it company-wide. A huge task. A year later - early 1982 saw my 90 year old Mother's mental and physical health deteriorating. A single career woman, an only child, I resided in my parents home - I was able to provide for her care at home, while I worked at setting up the EAP and travelled extensively. I was very cognizant that it was very demanding -- to be juggling the implementation of a new program with the physical act of caregiving when I was home. Coupled with those factors was the mental and emotional strain of watching the dearest person in my life in pain and slowly dying. My Mother died in October 1982, my performance review for that year clearly showed the impact of caregiving.

The review indicated that my performance had slipped one level. My then supervisor noted on the written review that it occurred in the three month period prior to my Mother's death. There was no unpaid Family Leave of Absence Policy in place at that time for caregiving. He was right, I was not at peak performance. Caregiving is a demanding, distracting job, especially caring for the elderly.

Responding to the needs of caregivers not only of the elderly, but of children, and spouses, Champion developed a Family Leave Policy for our non-represented employees to provide up to six months leave of absence, unpaid, with all benefits remaining in force. Both male and female, invoke the policy particularly when the employee has to determine their dependent's needs, assets, and resources available for both inpatient or outpatient treatment. Also, caregivers have the right to be with a troubled, ill or dying parent, without feeling punished for his or her absence from work. A distracted employee is not only a productivity problem but a possible safety hazard.

We know that employees need information about various topics indigenous to the aging and have developed such material. They include the booklet - "Caring for the Elderly," and pieces such as Prescription Drugs - which is targeted at the over 55 age group, including being printed in large type. The "Caring for the Elderly" booklet has been used by over 200 companies.

The local Champion EAP coordinator's job duties include researching governmental, private, local resources and to educate employees about these resources and their limitations in whatever state the employee's aging parents may reside. This is time consuming for the EAP, but allows the employee to focus more on his or her job performance and attendance.

Our educational efforts are about all aspects of caregiving, the physical, mental, emotional and legal through a series of Seminars at various Champion locations entitled, "Coping and Caring." These seminars are conducted by medical and legal experts at no cost to the attendees and include both present employees, their spouses and retirees. They help employees become aware of the need for planning for aging and the scarcity of paid, reliable caregivers.

Late 1987, Champion decided to provide EAP benefits to our retirees. We began with a pilot program in January 1988 to extend the EAP to our 500 retirees in the area surrounding the Bucksport, Maine mill. It is known within Champion as "REAP" or Retired Employee Assistance Program.

The retirees themselves designed the program to provide information, resources, speakers and social events to improve the quality of life for all ages of retirees. We have a volunteer corp that provides "Telephone Touch" for shut-ins and upon request, transportation to retiree functions, physicians, outpatient medical care, church services, etc. REAP is also working with local town's people and supporting the effort to develop a much needed nursing care facility in Bucksport, Maine.

REAP's type of human linkage is particularly needed in rural areas, when aging inhibits mobility and more people are living longer with no relatives to provide that human contact so necessary to life. The aging still have the need to touch, to interact with other human beings; the aging and their caregivers both deserve a quality of life.

We view ourselves as "Agents for Change" -- for our employees, retirees and other members of the community, including all the resource agencies as well as the medical profession itself. Change is emphasized as our nation enters the 1990's with the demographics shifting the focus to the aging population.

As "Change Agents," we believe that as EAP professionals in Champion we can also make the winter of aging not prison-like but pleasant, positive, while helping to enhance the lives and productivity of our current caregiving employees through a well developed Employee Assistance Program.

Thank you on behalf of all Champions.

# # #

November 14, 1989

REMARKS BY KAREN LEIBOLD

DIRECTOR, PROGRAM DEVELOPMENT

STRIDE RITE CHILDREN'S CENTERS

PRESENTED AT

"SHARING THE CARING: OPTIONS FOR THE 90S AND BEYOND"

A POLICY FORUM ON ELDER CARE

NOVEMBER 14, 1989

SPONSORED BY

REP. OLYMPIA J. SNOWE

AND

SEN. JOHN GLENN

"SHARING THE CARING"

November 14, 1989

Washington, DC

Share the experience that Stride Rite has had in almost 19 years of providing a supportive work environment for employees who are trying hard to be responsible workers as well as responsible family members. This environment creates a win-win situation for everyone involved.

There are many ways to help with dependent care. The key is flexibility.

There are three variables to consider before making a decision regarding the type of assistance to offer:

1. Employer Needs - What is the corporate culture, how much money can be spent, how will the assistance help reach corporate goals?

2. Employee Needs - Demographics - Do they need help finding care - paying for care - flexible work hours?

3. The Community - What are existing resources - What are the barriers in the community?

With the answers to these as a guide, employers can design a program of assistance that is effective.

Stride Rite has been providing on-site child care for close to 19 years. In addition, we provide paid maternity leave, resource and referral, family leave and flextime.

Benefits to Stride Rite: Better recruiting, less turnover and absenteeism, higher morale, a humane workplace, excellent community relations.

Benefits to Community: People can enter/remain in workforce - pay taxes, buy goods and services - become contributing members of community.

Benefits to Families: Less stress, the availability of quality, affordable child care, gets children off to a good start educationally.

26-799 - 90 - 2

The vision and commitment is now being extended into a new arena - that of eldercare. Eldercare is potentially a more dramatic and pressing issue for employers than child care has been. We are living in an aging society - and other demographics are shifting.

- Aging Population - over 85's are fastest growing segment of population.

- Illness - more elders living with chronic illness - new care options are necessary.

- Workforce - 70% of care provided by women who are now entering the workforce in record numbers. Also, as population ages, employees may be caring for elderly spouses as well as parents.

These factors combine to have a staggering impact on the work place:

- 1/4 - 1/3 of workforce is responsible for the care of an elder.

- The average caregiver spends 16 hours/week providing care.

- Employed caregivers lose an average of 5 work days per year due to other responsibilities.

- 10% of caregivers quit their jobs each year - after having worked an average of 11 years.

- Hidden health care costs due to employee stress.

A recent (1989) survey done by Fortune Magazine and John Hancock indicated that these may be a "daughter track" of employees who cannot pursue their career to its fullest due to caregiving responsibilities.

Executives that were surveyed reported that of their employees that had caregiving responsibilities, 60% were stressed, 40% need unplanned days off, and 30% needed extra planned days off.

70% of employeed caregivers reported that caregiving interfered with their work and 44% reported unexpeted time off.

We at Stride Rite are attempting to meet these new needs by developing an on-site intergenerational day care center. We will be providing care for young children and frail adults in a setting that is appropriate for each group. We will serve dependents of Stride Rite employees as well as families in the community.

We are working in collaboration with Wheelock College and Somerville/Cambridge Elder Services on this project.

The project has three major goals:

1. To provide the elder/child care services.
2. To provide a replicable model, both for public-private collaboration and for intergenerational care.
3. To research the effects of this kind of care on children, elders, their families and the workplace.

The center is expected to open in early 1990 with a capacity for 55 young children and 24 frail adults. The potential in a program such as this seems almost unlimited, and we are excited to be a part of an innovative project such as this.

The Stride Rite Intergenerational Day Care Center

Background

The Center

The Stride Rite Intergenerational Day Care Center is located within The Stride Rite Corporation's headquarters in Cambridge, Massachusetts. The Center is designed to provide day care to children and elders in the same facility.

The design of the Center allows a traffic pattern that encourages informal interaction between children and elders while also providing privacy for each group. The Center is divided into two separate wings which are connected through a large central area. The children's wing has four classrooms for different age groups; the elders' wing has three rooms designed for a variety of quiet and noisy activities. The central -- or middle core area -- houses administrative offices, a kitchen and dining facility, and a resource center which includes a conference room and library.

Among the special features of the facility: wide doorways which can accommodate wheelchairs; floor surfaces which make mobility easier for frail elders, and handrails along many corridors. An outdoor area is under design.

A total of 79 day care openings for children and elders will be provided at the Center. The program will serve 55 children between the ages of 15 months and six years, and 24 elders 60 years of age or older. As a continuation of Stride Rite's commitment to the community, approximately one-half of all openings will be reserved to serve low-income elders and children from the Somerville-Cambridge community.

The Center will serve as a teacher-training site for students and a research site for faculty from Wheelock College and Somerville-Cambridge Elder Services.

The Program

The Intergenerational Day Care Program will be implemented in two stages. The first stage is already underway -- introducing the children to the new facility and preparing them for the arrival of the elders. The second stage is expected to take place after the first of the year, when the elders arrive on site.

The Program will meet the physical, social and intellectual needs of each group through a carefully planned and supervised curriculum, which will foster regular daily contact between the elders and the children. Intergenerational curricula is expected to be fine-tuned as the program evolves. Activities might include (children/elders separate and together): reading and writing of stories; table games; celebration of holidays and birthdays; cooking and eating; arts and crafts, and field trips.

Ongoing research and evaluation of the program is expected to provide information on the effects of intergenerational care on children, elders, employees, employers, families and the community.

Research on the program's curriculum will be used:

- To develop college and graduate level curricula and training materials for professional intergenerational caregivers and specialists

- To produce curricula on aging and lifespan issues for preschool, elementary, middle-school and high school teachers

- To develop a "blueprint" for other organizations seeking to duplicate the Stride Rite model.

Workshops, seminars and support groups will also be designed to foster greater awareness of aging, lifespan, and caregiving issues among corporate managers and employees, families of participants, and the local community.

Benefits

- A model public/private partnership

- Intergenerational understanding

•Cost efficiency by bringing elders and children together in a single day care center

•Resource efficiency by uniting the unique services and expertise of multiple organizations

•Research that will contribute to the limited body of information that exists on the social effects and policy implications of intergenerational caregiving

The Public-Private Collaboration

The Stride Rite Corporation, Somerville-Cambridge Elder Services, Inc. and Wheelock College have joined forces to research the issues of dependent care and to create a national model for responding to the crisis in day care for children and elders. The collaboration has set three key objectives for the Intergenerational Day Care Program:

•To provide a replicable model for intergenerational day care

•To study to social effects and policy implications of work-based intergenerational day care

•To meet the local community's immediate elder care and child care needs.

The most important outcome of the model will be a "blueprint" for the development of intergenerational day care programs for other communities including: program curriculum; staff training manuals; evaluation tools; written research plan; documentation of implementation steps, and consultation services.

The Stride Rite Corporation

Stride Rite has a long history of interest in dependent care issues.

Part of the company's response to dependent care needs of employees has included an eight-week paid maternity leave and an18-week family leave policy. In addition, The Stride Rite Children's Center, the first on-site, employer-sponsored childcare center in the U.S., is considered a national model. The Center was founded in 1971. A second child care center was opened several years later.

Wheelock College

A leading academic institution specializing in early childhood education and family studies, Wheelock College will provide the academic framework necessary to support the research and curriculum development components of the Stride Rite Intergenerational day care Program. The Boston-based college was founded in 1888.

Wheelock will work to design an intergenerational curriculum that will bring together the children and elders at the Center in mutually supportive activities. Wheelock students will student teach at the Center and Wheelock faculty will conduct research for the development of training materials for intergenerational teachers.

Somerville-Cambridge Elder Services, Inc. (SCES)

SCES is a non-profit organization founded in 1972 to serve elders and their families living in Somerville, Cambridge and the greater Boston area. An experienced human-services agency, SCES provides services that enable elders to live in comfort, dignity and independence.

Among the many programs SCES offers is ElderLink. ElderLink provides services to employers and employees concerned about elder care. Seminars, referral services and one-on-one assistance to employees through ElderLink allows organizations to be responsive to the needs of employees caring for aging parents or other relatives.

For the Stride Rite Intergenerational Program, SCES will provide the expertise in screening and referrals of elder clients, as well as the development of the adult day care curriculum and training models.

SHARING THE CARING: OPTIONS FOR THE 90's AND BEYOND

Harry Posman
Acting Associate Commissioner for State and Community Programs
Administration on Aging

Today, there are several million "informal caregivers" -- relatives, friends and neighbors -- who are helping older persons, so that they may manage in their own homes.

It has been estimated that the need for caregiving will almost triple over the next four decades.

DEMAND FOR ASSISTANCE

By the year 2030, one out of every four persons in the U.S. will be over 60 years of age; a significant increase from today's ratio of one out of every six persons. The 75+ age group is increasing most; they are also older persons who need most care.

In 1984, 6 million or 23% of older persons living in the community had 1-5 health related limitations in activities of daily living (ADL's); 10% were receiving help.

In 2030, it is projected that as many as 13.4 million elderly persons may have activity limitations.

It is clear that the Nation is facing increasing demands for care. If the elderly do not receive it, they will end up in institutional settings.

SUPPLY

While the demand for caregiving increases, the "supply" of caregivers is decreasing. Traditionally, caregiving has been provided by daughters, sisters, wives and nieces. But the availability of these women is diminishing.

In a recent report, DoL projected that women will account for 64% of the net increase in the labor force. By the year 2000, women will comprise more than 47% of the total labor force.

The largest percentage of this increase will come from the 35 to 54 year old cohort, the very group most likely to be called upon to be caregivers.

RESOURCES

With this audience, I don't need to do much more than allude to constraints in public funds -- it affects all levels of government: Federal, State and local.

This condition is forcing us to think of new solutions for existing problems and issues; to use our other resources, person power and in-kind services for example, in more effective, efficient ways.

We must, at the same time, find creative innovative approaches that we can put into place now to avoid the potential problems that the changing demographics could bring about in the future.

THE PRIVATE SECTOR

Many in the private sector have responded to the needs of caregivers. Both experience and research has taught the more forward looking enterprises that supporting employees in their caregiving duties is good for company business. A new industry has grown up around this development: ELDERCARE.

Some of the most effective, energetic answers have come from corporate giants such as IBM and ATT. National organizations, such as the Washington Business Group on Health and the American Association for Retired Persons, have led in exploring ways to advance knowledge and experience in this area.

Many others in the private sector have not moved as far to provide assistance for their employed caregivers and have not reached out into the community to existing resources, such as State and Area Agencies on Aging.

THE NATIONAL NETWORK OF STATE AND AREA AGENCIES ON AGING

This network of agencies has the responsibility to collaborate with the private sector so that there will be comprehensive and coordinated systems of services for all older persons in each community.

In addition to arranging for services for older persons and respite care for caregivers, Area Agencies on Aging (AAAs) have reached out to both public and private sector organizations. They have offered one or more of the following:

- o work site caregiver fairs
- o work site seminars on caregiving topics
- o caregiver support groups
- o enhanced information and referral
- o counseling/case management for employees
- o and other services

Here is some anecdotal information across the country:

- The New York City Department for the Aging began a two-year demonstration project, Partnership for Eldercare. American Express, Morgan Guarantee and Philip Morris provide funding for this project. Two of these corporations act as test sites in developing models of eldercare services. Services provided include: information seminars; information and consultation for individual employees; and service referrals through the network on aging for older persons and their relatives.

- In New Jersey, the Union County Division on Aging is offering educational programs for private sector employees who are caregivers of older people. Employees from approximately fourteen private sector companies or corporations will be offered an opportunity to participate.

- In Maryland, Senior Reach is a statewide information campaign administered by the State Agency on Aging in partnership with the 18 local AAAs and ten major corporations. It serves as a link between employees and their families and the Senior Information Assistance

Program. Information on programs and benefits are provided to the private sector for publication in house organs and by other means of distribution.

- o In Atlanta, Georgia, the AAA provides consultation and referral services on behalf of corporate employees.

- o AAAs in Arkansas are providing similar services.

- o In California, the Central Coast Commission for Senior Citizens provides enhanced information and referral for employees of corporations.

This list could easily be expanded.

THE ADMINISTRATION ON AGING

To assist State and Area Agencies on Aging in promoting caregiving, the Administration on Aging supported approximately 40 grants, focusing on a range of issues from hands-on techniques; to respite care; on through to working with the private sector in developing Eldercare in the workplace.

One of the most recent activities was an event on September 22, the first national teleconference addressing the impact of caregiving on employees. The teleconference was sponsored by the University of Bridgeport and the National Council on the Aging with funding from the Administration on Aging. Offered at 12 sites around the country with support from AARP and Merrill Lynch, the teleconference was well received. Participating were representatives from Digital Equipment Corporation, The Travelers Companies, Chase Manhattan Bank, Marriott Corporation, Southwest Airlines, American Express, and IBM.

Also recently, the Commissioner on Aging convened a Roundtable discussion on issues involving Eldercare. As an outcome, a Task Force comprised of leaders from State and Area Agencies on Aging will develop a paper, which will be the basis for policy guidance to State and Area Agencies on Aging concerning their relationships with the private sector relative to Eldercare and caregiving.

CONCLUSION

This is the third year Senator Glenn and Congresswoman Snowe have focused on caregiving as a national issue. Their leadership in this very important area has been a positive

force in increasing the nation's consciousness about caregiving, both in the home and in the work place. It is a privilege to participate in this Policy Forum.

We, at the Administration on Aging, have been aware of the serious implications of caregiving. We conceive of services as an essential support for the often strenuous efforts of caregivers. We have used our resources to advance knowledge, to disseminate experience and to promote efforts throughout the Network on Aging to assist caregivers. One of our major goals for 1990 and beyond is to strengthen the family. We are committed to continued support for efforts to enhance and strengthen caregiving. Towards this end we shall seek to work collaboratively with the private sector.

REMARKS BY CARLA B. PITTMAN

DIRECTOR

FAIRFAX COUNTY, VIRGINIA AREA AGENCY ON AGING

PRESENTED AT

"SHARING THE CARING: OPTIONS FOR THE 90S AND BEYOND"

A POLICY FORUM ON ELDER CARE

NOVEMBER 14, 1989

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REP. OLYMPIA J. SNOWE

AND

SEN. JOHN GLENN

My name is Carla B. Pittman, I am the Director of the Fairfax Area Agency on Aging. The Fairfax Area Agency on Aging is located across the river in Suburban Northern Virginia. I have been the Area Agency Director since 1982 and with the County of Fairfax since 1973. Through these years I have seen significant changes in relation to human services and aging services.

Our agency is responsible for the operation of a comprehensive Plan of Aging services which includes community based services such as home care, transportation, home delivered meals, senior centers, housing, community education, volunteer programs and numerous other programs. We also are the lead agency for the operation of the Northern Virginia Long Term Care Ombudsman program that serves five jurisdictions. Our operating budget for 1990 is over five million dollars. Last year, Program Year 1989 we served over 10,000 older persons and their families. Each year we see a steady increase in the demand for service. We are fortunate to have a forward thinking Commission on Aging and a local government that is responsive to the growing needs and demands of the elderly population.

The Agency is responsible for serving the County of Fairfax and the cities of Fairfax and Falls Church. Currently we have a population of over 90,000 persons over age 60. Of significance, is the fact that for the population for Fairfax area is that there is a large number of persons who are in the age 55- 65 age category. What we are experiencing here locally is a greater number of persons who are in this age group who now have caregiving responsibilities. This situation and the projected increase in the elderly population age 75 and over has demanded that the local government develop a response that will meet current and future needs. We are the process of developing such a response that is future's oriented. The hope is that we will be able to pull all of our efforts together to develop a system that makes sense. The Human Service Council is working with our agency planners to develop a five year action plan for aging that will be cross cutting for the county.

The solution demands a total community response, we are working with the community, churches, civic associations, organizations, public and private sector agencies and consumers of service.This planning is something that cannot be done alone or in a vacuum. The key players in the development of such an aging plan are our consumers; the older person and the family. What is significant today, is that the family can no longer be defined in traditional

terms. Caregiving responsibilities cross over to all kinds of relationships and arrangements. What is important is that we develop supportative systems that will offer "help to the helpers". In order to do this effectively, we must meet the challenges that face all of us across the Country. These challenges include the fact that the current long term care system is fragmented; frequently services are not available in relation to current needs. Sheer demographics demonstrate that future projections of need on our continued course without planning will result in greater lack of support for our caregivers and greater unmet need. Service systems do not always talk to each other and people get lost in the cracks. Eligibility systems are confusing and even the most educated knowledgeable person can become lost in an endless merrygoround of referrals with no results. A comprehensive response means that we must embark upon a deliberate action of systems building. The goal should be that no older person or their family should be denied service if they need it.

I would like to talk to you now about what we have done and what we are planning. First of all, in 1983, the Board of Supervisors authorized the Area Agency on Aging to conduct an Elderly Needs Assessment to determine the current and future demands of the elderly population. Generally what happens is that agencies develop needs assessments which validates the needs of the population and this goes up on the shelf and becomes dusty. What was different from the usual response was the Board of Supervisors commissioned a "blue ribbon" Task Force to develop a blueprint and strategic plan in order to respond to the needs which were identified by the Elderly Needs Assessment. The Report Strategic Perspectives on Aging: Resources and Needs (SPA) developed an operating framework and philosophy related to the local government response. All planning activities currently underway are developed in relation to this report.

The general framework provided from the report was:

* First and foremost, the individual and family are responsible for meeting their own needs. Local government has a role in enabling individuals and their families to meet their own need through information, education, support, and services that promotes independence and self sufficiency.

* Second, when there is a market demand for services, the private sector is the most appropriate provider of services. Local government has a role in promoting private sector response through such techniques as collaboration, training, and providing technical assistance when appropriate.

*Finally, local government should be the provider of last resort for service needs when there is no private market response and for those individuals for whom the public sector is the most appropriate provider of service.

This framework has been instrumental in all of the planning and development of the agency including the following efforts:

* The Senior Center Study which develops a network of senior centers, housing and adult day health care centers that will be accessible and respond to "aging in place" issues of participants. We just finished the five year Capital Improvement Plan which will lay out these systems.

* The re-organization of the agency in relation to priority setting and response of the SPA report. Currently the agency has a large volunteer driven based effort due to changes in programming. We currently have over 1100 volunteers who are functioning in every capacity of the organization. Examples are the Consumer Housing Information Service for Seniors run in conjunction with AARP, a Medical Forms Assistance program to help elders and their families fill out insurance forms, and volunteers who help with the computer planning and community education operations.

* The Development of the Corporate Eldercare Task Force which includes the public, community based and private sector organizations. This Task Force will be examining the private sector response to elder care needs of employees;the public sector response to elder care needs of employees; and determine for employers the nature and extent of eldercare needs of the employee population. This is an example of how all organizations need to work together to build a coordinated response. Employers will be surveyed to determine current elder care needs.

* A Home Care Task Force consisting of over 40 public and private organizations and consumers has developed for the Board of Supervisors a comprehensive plan to address the availability, affordablity and quality of home care for persons. This report includes broad based recommendations relating to the recruitment and training of home care workers and a large effort related to consumer education and consumer protection through the Ombudsman program. All of these efforts will be undertaken in partnership with the community.

These are few of our efforts. In summary, in order to meet the challenges of the 90's and beyond we must be creative and work together in partnership in order to meet the needs of the older person and their support system. I believe that every older person has the right to have a support system. We should recognize and give the "helpers" what they need to keep helping. If an older person does not have a support system available through the traditional methods we have a responsibility as a community to create it.

SECTION II

Washington Business Group on Health

Institute on Aging, Work, & Health

PUBLIC/PRIVATE PARTNERSHIPS IN ELDERCARE

Prepared for the

Subcommittee on Human Services

of the

U.S. House of Representatives
Select Committee on Aging

in conjunction with the Policy Forum on Elder Care
November 14, 1989

by

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The Washington Business Group on Health (WBGH), a non profit membership organization of Fortune 500 companies, has sought to stimulate greater corporate interest in and support of initiatives for employees with eldercare responsibilities as part of its Partnerships in Aging project, a joint initiative with the U.S. Administration on Aging (AoA).

Partnerships in Aging, developed by WBGH's Institute on Aging, Work and Health, represents a national initiative to promote public/private sponsorship of programs for older adults. With support from the Administration on Aging and private employers, the Partnerships in Aging project has encouraged state and local business coalitions and their member companies to work with State and Area Agencies on Aging on a variety of aging-related topics.

Components of the project include guidebooks, reports, conferences, public hearings and a quarterly newsletter, **"Together on Aging"**, which highlights public/private partnership activities. Most recently, the Policy Center on Aging at Brandeis University's Heller School has collaborated with WBGH to write **"Eldercare: An Issues Overview"**, providing policy makers in both the private and public sectors with information about the challenges caregivers face in the workplace, along with an outline of policies and programs designed to assist them. WBGH will also be issuing an employer's guide to eldercare which will be available in Spring, 1990.

Partnerships in Aging activities also have included seed grants of $3,000 allocated to eight sites to develop model programs in the following areas: eldercare; work and retirement; and health promotion/health education for older workers and retirees. In each of the sites, businesses worked in tandem with community aging agencies in the design of the programs.

Four sites involved in the Partnerships in Aging project developed a variety of eldercare programs which are summarized as follows:

BOSTON, MASSACHUSETTS

The Health Action Forum (HAF) of Greater Boston, in a joint

effort with the State's Department for Elderly Affairs and the Boston-based Merrimack Valley Business Group on Health developed its Workplace Caregivers Project with six New England-based companies: Harvard Community Health Plan, New England Telephone, Mayo Health Facilities, Houghton Mifflin Corporation, Boston Edison, and Wang Laboratories, Inc.

At four of these worksites, employees participated in a survey designed to determine the nature and extent of caregiver needs and responsibilities. The findings from these surveys are reviewed and analyzed in a report issued by the Health Action Forum entitled **"Eldercare: The State of the Art."** This report, which was published by an in-kind contribution by **Houghton Mifflin**, includes a summary of the range of caregiving responsibilities identified, as well as the original survey instrument.

Key findings of the study include the following: approximately one-third of employees have caregiving responsibilities, over three-quarters of the caregivers have been providing care for over a year, and five to seven percent of the caregivers missed six or more days of work annually due to caregiving responsibilities.

Responding to the needs of these caregivers, a number of programs and products were developed through the Partnerships project. Staff from HAF conducted a series of lunch-time seminars on such topics as respite support for the caregivers, community resources, legal and financial concerns, and Alzheimer's Disease. The **Houghton Mifflin** Corporation developed a lunch-time Alzheimer's support group. The majority of the 15 participants in this group had family members with the illness, consequently these employees, having concerns about their own health, wanted to learn more about Alzheimer's Disease.

Other activities that are being developed include a caregiver's fair that will be held at **Houghton Mifflin** in February 1990. In addition, a telephone hotline for employee caregivers is targeted to begin in February 1990. Several companies will participate in the hotline for a three-month trial

period, while **Bull Information Systems**, the French-owned computer manufacturer, will participate in and provide seed funding for the project for one year. The Boston Visiting Nurses Association will manage the hotline.

In addition to the report of survey results, HAF developed other written products for the project, including **"Eldercare: A Caregivers Manual"** which provides explanations of many of the support programs for caregivers, such as housing, health, Medicare and financial planning. Other topics include stress management and on-the-job time management for employees who care for older adults.

Finally, HAF produced a directory of providers offering eldercare services to corporations in Eastern Massachusetts. This guide is targeted to benefit managers and provides an inventory of private, non-profit and for-profit organizations in the Boston area which are available to provide caregiver support and assistance to local companies. The providers represent an array of services including information and referral, seminars, support groups, comprehensive health and social assessments and arrangements for long-distance caregiving. Additional support for all of the projects developed by the Health Action Forum was provided by the Robert Wood Johnson Foundation.

HARTFORD, CONNECTICUT

Collaborative efforts of the North Central Connecticut Area Agency on Aging, the Greater Hartford Chamber of Commerce and the Business Coalition on Health have resulted in a benefit manager's guide to eldercare entitled **"Employee Caregivers: Demands on the Workplace"**.

The guide describes why employers should be concerned about caregivers and presents facts about caregiver needs. It also provides information on where employers can find information and help on caregiver issues as well as descriptions of innovative programs. Specifically, the booklet profiles the eldercare programs of several Connecticut-based companies including **Champion International, People's Bank, Pitney Bowes, The Travelers Companies, and Remington Products, Inc.** The Hartford

Insurance Company provided staff support to the project through a time-release arrangement.

Champion International has developed a booklet entitled **"Finding Help for Older Relatives"**, which assists employees in learning how to access services for the elderly throughout the United States. In addition, **Champion's** eldercare initiatives include personnel policies that assist employees and retirees who have caregiving responsibilities, including up to three visits to a licensed psychiatrist or psychologist per year. Other companies profiled in the booklet include **People's Bank** which offers a flexible benefits program for employees, and **Pitney Bowes** and **Remington Product's** lunch-time discussion seminars on issues relevant to caregivers.

JACKSON, MISSISSIPPI

The Mississippi Council on Aging and the Capital Area Personnel Association conducted a survey to identify employee caregiving and long term care needs at two major private sector employers, **Mississippi Power and Light Company**, and **Southern Farm Bureau Life Insurance Company**.

Survey results indicated that approximately 20% of respondents had caregiving responsibilities. Caregivers indicated a need for information and referral services particularly in such areas as community resources, health information, home care and how to choose a nursing home.

Survey research and information for caregivers was published in the Aging Communicator, a newsletter of the Central Mississippi Planning and Development District/Area Agency on Aging. This newsletter is disseminated to employees at the participating companies.

Specific projects to address the needs of employees who care for elderly relatives are being developed as a result of survey findings. For example, lunch-time seminars on the availability of resources for caregivers, and information on services provided by Area Agencies on Aging may be offered.

This Partnerships in Aging project was the impetus for the development of the **Leadership Jackson Group** which is trying to

establish an eldercare foundation in the city. This foundation would be a mechanism to generate funds to provide homemaker and case management services. Businesses involved to date include: **Trustmark Bank**, the **State Attorney General's Office**, and **Spruill Advertising**. The **Mississippi Valley Gas Company** has also expressed interest in the project.

CLEVELAND, OHIO

The Health Action Council (HAC) of Northeast Ohio, a membership organization of Cleveland-based employers, and the Western Reserve Area Agency on Aging developed an information and training series for employee benefit managers on eldercare as a retirement planning issue. **Stouffers Corporation** and **Ameritrust Bank** served as corporate advisors.

The retirement planning training series was made up of modules including **"Overview of Elder Care and the Workforce"**, **"Health Care Coverage Decisions"**, **"Understanding Medicare"**, **"Understanding Long Term Care"**, and **"Financial Planning for Long Term Care"**. The modules provide resources to assist employers in addressing the concerns of working caregivers.

Included in the eldercare section of the training series are a variety of resources including background information, needs of the workforce and intervention options, and a sample survey to determine the extent of employee eldercare responsibilities.

OTHER ACTIVITIES

The seed funds provided by the Partnerships in Aging project have enabled participants to develop model pilot programs which can be replicated by other organizations. In addition to the eldercare projects developed through the Partnerships in Aging program, a number of other public/private partnerships focusing on other aging-related issues have been implemented through the WBGH/AoA initiative.

In Delaware, for example, the Division on Aging is involved in a series of health promotion initiatives which involve partnerships between the State Unit on Aging, other state agencies and private employers. One initiative, the "RX CHECK" program, is a health maintenance resource for older adults. The

program has included the development of a personal health record booklet distributed through senior centers and other institutions.

The RX CHECK book encourages users to keep physicians' names, addresses and phone numbers, emergency contacts, and to maintain a record of medications taken. In addition, it provides useful advice on medication use and possible side-effects. The RX CHECK project will be continued through grant assistance from the **Nemours Foundation.**

In Atlanta, the Health Care Alliance, a membership organization of employers and providers, developed the "HealthStyle Wellness Program" which includes a health risk assessment and questionnaire, a computer software program to analyze results, and health education sessions and screening services. A total of 500 older adults participated in the program. Each of the participants were retirees of three major Atlanta-based firms: **IBM, Atlanta Gas Light Company,** and **Delta Air Lines.** The Alliance coordinated with the Pro Health Task Force of the Atlanta Area Agency on Aging and developed a strategy for helping the participating retirees take more responsibility for learning about and maintaining their own good health.

The retirees participated in a health assessment program which included glaucoma, hearing, blood pressure, and cholesterol screenings, among others. Since HealthStyle's inception, a local Atlanta chapter of the **United Auto Workers** has tailored the program for its members.

FUTURE PROJECTS

WBGH and AoA will once again be issuing eight seed grants through a Request for Proposals (RFP) format in March 1990. This RFP will go out to State and Area Agencies on Aging and business coalitions nationwide. A National Advisory Board has been established to select the participating sites.

ALZHEIMER'S
ASSOCIATION
Someone to Stand By You

THE ALZHEIMER'S ASSOCIATION'S "PARTNERSHIPS IN PROGRESS"

Since its founding in 1980, the Alzheimer's Association has relied upon the support of various membership organizations. These organizations fund programs and services the Association offers to Alzheimer victims, caregivers and their families. Without these generous donations, the Association could not continue its search for the cause, cure and treatment of Alzheimer's disease, nor could it continue to provide the services that so many individuals have come to rely on.

Regardless of the financial amount of the donation or the number of volunteers recruited, the Alzheimer's Association is truly grateful for the efforts of these membership organizations.

Membership organizations supporting the Alzheimer's Association are from all over the country and represent a variety of professional, social and cultural backgrounds.

For example, in 1987 the National Association of Retired Federal Employees (NARFE) made a $500,000 commitment to the Alzheimer's Association establishing the National Alzheimer's Research Fund Endowment (NARFE/NARFE). Two years later in 1989 NARFE committed itself to another $500,000 contribution to the Association.

Founded in 1921, NARFE is comprised of retired U.S. Government at District of Columbia employees and their spouses. As an organization, NARFE actively funds programs and services related to the problems of the aged and aging.

In addition to its generous financial support, NARFE encourages its members throughout the country to work with local Alzheimer's Association Chapters in providing support services for patients, caregivers and their families. Volunteers often sit with Alzheimer patients, giving caregivers precious time for themselves. They also work with Chapters, helping to raise needed funds for community programs.

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ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOC. INC.
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Another example of a "partnership in progress" is that of the Alzheimer's Association and the Independent Telephone Pioneers Network (ITPA). Thanks to the support of ITPA, the Alzheimer's Association is successfully increasing the public's awareness of Alzheimer's disease and the services available to patients, caregivers and their families through several video projects.

The first product developed through these cooperative efforts is the new, "Introduction to the Alzheimer's Association" video. This video and its accompanying manual were created for Chapter use in increasing public awareness of Alzheimer's disease and the Association. Funding of the video by ITPA has made it possible for the Association to provide each one of its 207 Chapters with one video and accompanying manual at no charge.

The Association also receives funding and support from the following organizations; Sigma Beta Sorority, Beta Sigma Phi, National Catholic Society of Foresters, United National Real Estate, TWA Clipped Wings, Grand Lodge-Daughters of Scotia, Auxiliary of the National Rural Letter Carriers' Association and the New Jersey Association of Health Care Facilities.

Standing by you:

Family support groups

Alzheimer's Disease and Related Disorders Association, Inc.

Someone to stand by you

Coping with Alzheimer's Disease (AD) or a related disorder does not have to be a lonely experience, although it is common to feel alone, to think that no one can understand what is happening to your life. Participating in a family support group can help, by giving you a chance to share your feelings with others who do understand because they too have a loved one with dementia.

If you are a caregiver, you probably are aware that you will need help and support as the disease progresses. However, caregivers can easily become isolated with their patients because of the demands of caregiving, the forced changes in lifestyle, the loss of friends or the lack of family assistance. A family support group can help, by giving you a chance to meet others who also are facing the caregiving struggle. Support groups were established so that those who care for someone with dementia do not become "victims" of the disease themselves.

What is a support group?

A family support group is made up of caregivers, family members and friends of those with AD or a related disorder. Although these people begin as strangers, they quickly become friends and, in a sense, a family.

The support group leader(s) may be a family member and/or a health care professional. The meeting may focus on emotional support and sharing experiences, or it may focus on education, with experts speaking on topics such as legal issues, nutrition,

caregiving techniques and community resources.

The number of participants will vary, in some cases depending on the format. For instance, educational groups are usually larger. However, the ideal size for a support group is 6 to 12 members.

Meetings are usually held monthly or bimonthly at members' homes, a hospital, church, library, nursing home or senior center.

The purpose of an Alzheimer's Association support group is to offer families support and information that is specific to dementia. Some Alzheimer's Association Chapters have support groups especially for adolescents, male spouses, adult children caring for a parent, family members of nursing home residents, or widows and widowers. Some Chapters also have a special orientation for family members of a newly-diagnosed patient.

Family support groups that are sponsored by an Alzheimer's Association Chapter are open to the public and free of charge. These support groups depend on the Chapters they are affiliated with to provide resources such as literature, updates on legislation and research, and newsletters. Alzheimer's Association Chapters serve larger areas than the support groups and they provide resources to the community as well.

Alzheimer's Association support groups encourage members to share information, give and receive mutual support and exchange coping skills with one another. Support group members share practical suggestions for caring based on their caregiving experiences. Caring for a dementia patient requires different techniques than those needed to care for a patient who is not

Rona Talcott

cognitively impaired. Experienced caregivers have found that some methods of providing care, ideas that may not be found in books or articles, can make caregiving easier. Sharing those ideas in a support group can prevent caregivers from having to "re-invent the wheel."

The support group setting also assists families in learning about and locating community resources, such as adult day care and transportation services. Through sharing common experiences, families can obtain consumer information, such as listings of physicians who are familiar with dementia or nursing homes in the area that accept dementia patients.

Perhaps what is most important about a support group is the atmosphere of caring, frankness and confidentiality it provides. Family members need the freedom to express their emotions without feeling guilt, and caregivers need the positive reinforcement that can be given by others who know the hard work involved in providing care. A support group gives its members the chance to vent their frustrations, anger and disappointments, as well as share their successes in a safe, non-judgmental environment. In the process, members take a first step in

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restructuring their lives by forming new relationships with each other.

Why do I need a support group?

Attending a support group is often difficult at first. It takes time to feel comfortable sharing your problems with people you do not know. However, the experience of many family members is that once they opened up, they found that their problems were not so different from those of other support group members. Suddenly, the people they were sharing with were not strangers at all, and by sharing with others in the same situation they felt less alone.

If you are having difficulty talking to family or friends about your feelings, you may find that it is easier to express yourself in a support group, where you can be honest with others who are facing similar problems.

A support group also can help you feel more in control of your life, by helping you understand more about the disease. Because you will have heard how others have coped or are coping with similar situations, you will know what to expect. By sharing with those people and learning from their experiences, you may find it easier to solve problems and make difficult decisions.

Through participation in a support group, you will be better prepared and perhaps feel less devastated as your loved one's condition becomes worse. You also may be able to find some hope, from seeing that others who have been caring longer have survived the caregiving experience.

Finally, a support group can give you encouragement and moral support. The

group's members can help you rebuild the self-esteem that may have been damaged in the caregiving process. In many cases, the support group members can become a second family, especially if you are not receiving help from family members or friends.

What if . . .

you cannot attend the support group meeting at the time it is normally scheduled? If you work during the day or you cannot see at night to drive, ask the Alzheimer's Association Chapter if there are others in your area who would like to meet at a different time and who may be interested in starting another group.

you do not drive? Ask the Chapter if a support group member lives in your area and could pick you up, or if there are transportation services you could use.

you cannot leave your patient? Ask the Chapter if respite services are available. Sometimes the support group will have a care provider(s) available during the meeting so family caregivers can attend while someone looks after their patients.

you already have too many demands on your time? Try attending a support group meeting at least once. For many caregivers, attending their support group meeting becomes the single best hour-and-a-half they spend each week. It is the one time and place where they can relax and be themselves.

your circumstances make it impossible to attend? Ask the Chapter if it has a telephone support network established for housebound caregivers.

you are not the primary caregiver? If you live miles away from your loved ones, a local support group still can be useful by helping you understand what the caregiver is facing so you can offer assistance. It can be the source of caregiving suggestions and research updates that you can share with your loved one's caregiver. A support group also will give you the opportunity to share your emotions and fears with other family members. Their understanding and experience can help you cope with your situation.

"Support groups provide a sense of community. It's a place where you can go and, without saying a word, be understood. It's a bond, a community, a trust you have for each other."

—Harriett Adelstein, OTR
Alzheimer's Association–Chicago Area Chapter

How do I find a support group?

Check your local phone book for the listing of the nearest Alzheimer's Association Chapter, or call the Alzheimer's Association toll-free telephone number for a Chapter referral: 1-800-621-0379 (in Illinois, 1-800-572-6037).

If there is not an Alzheimer's Association Chapter in your area, the nearest Area Agency on Aging (AoA) office should be able to provide you with information on support groups. If you are interested in starting a support group, contact the nearest Alzheimer's Association Chapter or the Association's national office.

This brochure is made available by the Alzheimer's Association through a generous grant from the

Independent Telephone Pioneer Association

For more information and a complete list of titles, contact your local Alzheimer's Association Chapter or call the Association's toll-free number.

ITPA

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SECTION III

A NATIONAL SURVEY OF CAREGIVERS

FINAL REPORT

CONDUCTED BY:

OPINION RESEARCH CORPORATION
WASHINGTON, DC

CONDUCTED FOR:

AMERICAN ASSOCIATION OF RETIRED PERSONS
WASHINGTON, DC

AND

THE TRAVELERS FOUNDATION
HARTFORD, CONNECTICUT

SEPTEMBER 1988

A PUBLICATION OF HEALTH ADVOCACY SERVICES SECTION, PROGRAM DEPARTMENT, AMERICAN ASSOCIATION OF RETIRED PERSONS. RESEARCH FUNDED BY THE AARP WOMEN'S INITIATIVE AND THE TRAVELERS FOUNDATION.

NATIONAL SURVEY OF CAREGIVERS FINAL REPORT

EXECUTIVE SUMMARY

o How many caregivers are there?

Estimates of the number of U.S. households containing at least one caregiver range from approximately 1.5 million to 7 million, based on how caregiving is defined. Table 1, below, presents the estimated incidence of caregivers for several commonly used definitions of caregivers.

Table 1. Incidence and Population Estimates for Caregivers

Population Estimates And Incidence	Definition
7.8% 7 million households	- Provides unpaid assistance to 50+ year-old within the past 12 months consisting of <u>either</u> of the following: - 2 IADLs, activities for managing one's own affairs, including: -- managing finances -- grocery shopping -- housework -- preparing meals -- transportation -- administering medicine <u>OR</u> - One ADL, personal care activities, including: -- dressing -- bathing -- feeding -- toileting -- transferring
4.2 percent 3.7 million U.S. households	- Current caregivers only
3.1 percent 2.8 million U.S. households	- Current <u>and</u> past caregivers - 2+ ADLs only
1.7 percent 1.5 million U.S. households	- Current caregivers only - 2+ ADLs only

o Who are the caregivers?

The burden of caregiving most frequently falls on women. The typical caregiver is likely to be a woman in her mid-forties who is also employed outside the home in a white-collar profession. Caregivers often live in a "family" household with a spouse and children. The average income of caregivers is $26,100, although 11 percent live in households with incomes of less than $10,000 and 10 percent earn more than $50,000.

Nearly two-thirds of those surveyed consider themselves to be the primary care provider (63%). The individual surveyed did not necessarily become the primary caregiver by choice. In one-third of all situations primary caregiving responsibility has fallen to this individual because he or she is the only one who lives close to the care recipient (33%). Another 25 percent say they are the primary caregiver because they have no choice -- no one else will do it. Nearly one-in-five (18%), however, have assumed primary caregiving duties because they feel they have a closer relationship than others with the care recipient.

As shown in Table 2, primary and secondary caregivers differ from one another demographically. Primary caregivers tend to be older; 20 percent are at least 65 years of age, compared to only nine percent of secondary caregivers. As one might expect, more primary caregivers are retired (20% vs. 9% of secondary caregivers) and, consequently, not currently employed outside the home (49% vs. 31%, respectively). Given the fact that many retirees live on fixed incomes, it is not surprising that primary caregivers tend to live in less affluent households.

Table 2. Caregiver Profile

(Base)	Total (754)	Primary Caregivers (475)	Secondary Caregivers (247)
Sex			
Male	25%	23%	28%
Female	75	77	72
Age			
Under 35	28%	20%	42%
35 - 49	29	28	32
50 - 64	26	31	16
65 or Older	15	20	9
Median Age	45	49	38
Marital Status			
Married	66%	66%	66%
Not Married	34	34	34
Children in Household			
Yes	39%	34%	48%
No	49	51	43
Current Employment			
Full-Time	42%	38%	49%
Part-Time	13	12	17
Retired	16%	20	9
Not Employed/Homemaker	27	29	22
Household Income			
Under $10,000	11%	13%	8%
$10,000 - $19,999	17	17	18
$20,000 - $29,999	19	19	21
$30,000 - $49,999	22	20	24
$50,000 or more	10	10	11
Median Income	$26,100	$25,700	$27,100
Primary Caregiver			
Yes	63%	100%	0%
No	33	0	100

o What responsibilities do caregivers have?

Caregivers generally care for a relative (85%), most likely their mother (28%), grandmother (12%), father (12%), or spouse (10%). The older person is likely to be 75 or older (60%). They most often suffer from a chronic physical disability which renders them housebound. One-fourth of the time the housebound care recipient is also either wheelchair-bound or bedridden.

Despite the prevalence of physical disabilities, only about a third of all care recipients live in the same household as the caregiver (37%). Few are confined to a nursing home (5%) or some other assisted-living arrangement (8%). One-half (50%) of all care recipients still live in their own home in close proximity to that of the caregiver. Of those who live on their own, 74 percent live within 20 minutes.

Providing care for someone who has physical limitations requires a strong commitment on the part of the caregiver. On average, caregivers have been providing 12 hours of care per week. A small group of caregivers -- 11 percent -- give constant care, while 28 percent give care eight hours or less per week.

Caregiving responsibilities often include providing personal services. On average, caregivers provide assistance with two ADLs. More than two-thirds (68%) of the caregivers surveyed provide assistance with one or more ADLS; 19 percent provide one; 15 percent provide two, and 33 percent provide three or more. Almost all caregivers assist with IADLs, primarily grocery shopping (82%), transportation (79%) and housework (75%).

Table 3. Caregiving Responsibilities

ADLs Provided	Percent
	%
Walking	46
Dressing	41
Bathing	38
Toileting	29
Feeding	27
None	32
IADLs Provided	**%**
Grocery shopping	82
Transportation	79
Housework	75
Preparing Meals	68
Managing Finances	65
Administering Medicine	45
None	1

On average caregivers have been providing assistance with ADLs and/or IADLs for the last two years and expect to continue to do so for an indefinite period of time. While 26 percent have been providing care for one year or less, another 26 percent have been providing care for six or more years. Notably, more than one-third of constant caregivers (35%) have been providing care for six or more years.

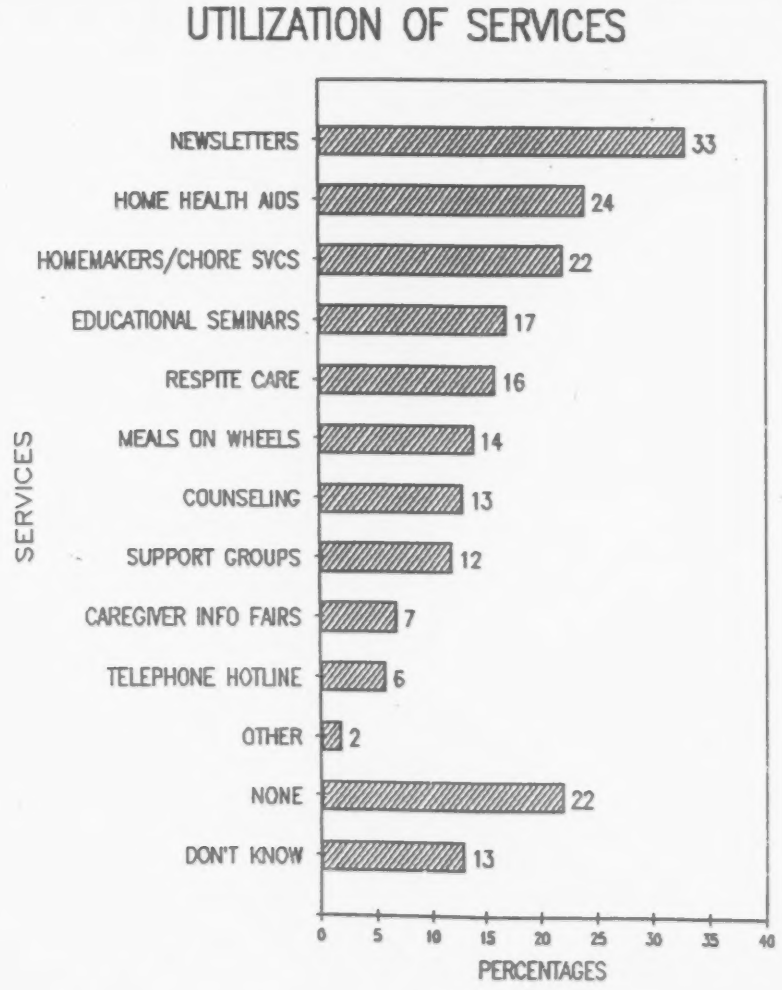
Time spent on caregiving may create stress by leaving less time for other activities. This is evidenced by the finding that one-in-two caregivers report having spent less time on leisure activities than before (51%). One-third reportedly have either spent less time with their own family than before (34%) or paid less attention to their own health (33%), while more than one-fourth (28%) have been unable to take a vacation.

The burden is particularly great for primary caregivers. Only 21 percent of primary caregivers report that they have made no changes in their lifestyle compared to twice as many secondary caregivers (40%).

o What services do caregivers use?

Most caregivers seek some assistance from outside sources in performing their duties. About two-thirds (65%) of all caregivers have utilized at least one social service, most provided by a community or government agency. The largest single segment (33%) of caregivers report having read newsletters about caregiving (33%). Another fourth have utilized home health aides (24%) or homemakers and chore services (22%). These latter two services are almost equally likely to be provided by friends and family, community and government agencies, or paid services. Fewer, though substantial, numbers of people have sought help with respite care, meal services, or counseling and emotional support.

Non-utilization of services is generally attributed by caregivers to little or no need for the service. Only a small number of caregivers who have not utilized services are reportedly not aware of them, suggesting the need for heightened public appreciation of available supports. Few caregivers report not using services either because they cannot afford them or that they are not readily available.



- **What types of assistance or services do caregivers perceive they need?**

Caregiver needs relate primarily to wanting to be kept up to date with developments affecting their specific situation and to seeking help in dealing with the bureaucracies to obtain services. The majority of all caregivers say they need information about developments in medicine and health care (42%), help in dealing with bureaucracies to get services for their care recipient (39%), or updates on federal and state legislation affecting their situation (35% to 38%).

About one-in-three caregivers see a need for emotional support and respite care, particularly primary caregivers and those providing constant care. Caregivers want someone to talk to when they are overburdened (32%), some free time for a vacation (31%), and/or someone with whom to share coping strategies (30%). However, caregivers apparently feel they can cope well overall with the physical demands, since fewer than one-in-five caregivers reportedly need assistance providing ADLs (17%).

In addition to primary caregivers and those who provide constant care, other groups of caregivers who report higher levels of need include persons who provide three or more ADLs and those who take care of individuals who are housebound, bedridden or confined to a wheelchair. Caregivers who are members of a racial minority, live in lower income households, are unmarried, and have children still living with them, also report higher levels of need.

Results of a special analysis indicate that five "natural" caregiver groups exist, arrayed along a continuum of need for services. At the low end of the continuum are Group A caregivers who say they have no need for any of the services and who have previously utilized available services only to a very limited extent. This group, which comprises 24 percent of the caregivers surveyed, provides less intense care, both in terms of types of activities and time (i.e., fewer ADLs, less time weekly). They are more likely than others to be white and to benefit from spousal support. The recipients of their care tend to be healthier; fewer are housebound or bedridden, with a greater number living in their own home or apartment.

Similar to Group A are Group B caregivers. They comprise another 24 percent of caregivers. While they have some need for services, it is at a very low level. Demographically, more of these caregivers are men, under age 35, living alone, and likely to be taking care of a grandparent, not a parent.

In the middle are Group C caregivers (23%). This group indicates a moderate need for services, particularly information updates, and makes a moderate time commitment to caregiving.

Toward the high end of the continuum are two groups of caregivers. The fourth group (Group D), comprises 19 percent of those surveyed. These caregivers are more needy than those in the middle, and express a high need for all services, particularly those relating to emotional support and respite. They are more frequently dependent on support services such as counseling and home health aides. They spend at least 15 hours per week caregiving, often providing at least three ADLs to housebound or bedridden individuals. They may have fewer informal support systems, since a large proportion are women who are separated from their spouse.

At the high end of the continuum are those with a 100 percent need for more of all services (Group E). While they constitute only 10 percent of all caregivers, they bear a heavy burden of responsibility, performing more ADLs, and consequently, spending more time each week on caregiving activities. They are more likely to be women, minorities, and have children living with them, and less likely to be married or over the age of 65. Behaviorally, these caregivers are among the most likely to have already utilized available services. The recipients of their care are the most disabled. Larger numbers are housebound, and of those, more are either bedridden or confined to a wheelchair.

Table 4 on the following page illustrates the varying level of perceived need for different categories of services.

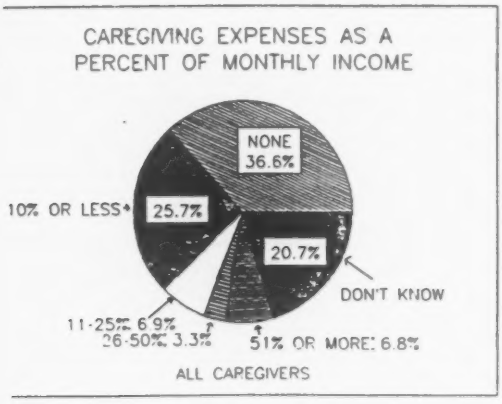
Table 4. Perceived Level of Additional Need for Services

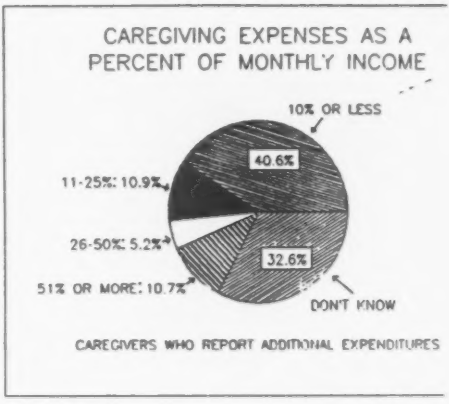
Category of Service	Caregiver Group A	B	C	D	E
General -- Includes help in selecting a nursing home, information about finances, help dealing with bureaucracy, and general information about the aging process.	0%	0%	31%	88%	100%
Updates -- Includes updates in state and federal legislation, information about health and medical developments, and a central place to go for information.	0%	0%	46%	80%	100%
Emotional Support & Respite - Includes someone to talk to and share coping strategies with, and free time for a vacation or to run errands.	0%	2%	32%	92%	100%
Housework -- Includes help with light housework, heavy cleaning, shopping, ADLs, meal provision, and "daycare" while caregiver works.	0%	1%	21%	81%	100%

o What are the economic implications of caregiving?

Caregiving often involves additional financial responsibility on the part of the caregiver. Two-fifths of all caregivers report that they have incurred at least some additional expenses as a result of caregiving. However, it appears that it may be difficult for caregivers to determine the true economic costs associated with these responsibilities, since nearly one-third of these caregivers cannot estimate the actual amount of their expenses.

As shown below, about one-fourth spend up to ten percent monthly on such expenses (26%) and seven percent spend either between 11 and 25 percent of their incomes or more than 25 percent. Just over one-third (37%) of all caregivers say they incur no additional expenses. However, as many as 21 percent say they can not estimate the extent of their expenditures.





Overall, caregivers who say they have incurred additional costs estimate that these expenses amount to about seven percent of their monthly income. Certain groups of caregivers spend a larger percentage of their income on caregiving expenses than others. Demographically, these caregivers tend to be over 65, not currently employed, members of a racial minority, and living in a household with an income of under $10,000 annually. They tend to provide more intense care to more disabled individuals. Often, they are providing constant care to their spouse.

As shown in Table 5, bbelow, the magnitude and types of caregiving expenditures vary. Onn average, these expenses total $117 per month. The largest numbers off caregivers report that they have incurred expenses related to trravel, telephone bills, and special diets or medicines. While mostt widely incurred, these categories of expenditures constitutte a lower average monthly expense than many others. Health-relateed expenses, such as in-home nursing care, hospital care, and homme health aides, while not as widely incurred, are reportedly far morre costly on a monthly basis. One-time expenditures such as aadaptations to the care recipient's residence ($240) or the purchasee of medical equipment ($158) also tend to be more costly. Each of tthese two expenses were incurred by 15 percent of caregivers.

Table 5.. Monthly Caregiving Expenditures

Type of Expense	Percent Who Incurred	Average Amount
Travel	31	$ 29
Telephone bills	25	$ 25
Special diets & medicimes	24	$ 57
Doctors fees	17	$ 55
Homemaker/cleaning serwice	12	$ 76
Hospital care	12	$275
Home health aides	10	$ 63
Respite care	7	$ 83
In-home nursing care	6	$238
None	39	N/A
Median	N/A	$117

o What are the implications for caregivers working outside the home?

One of the primary objectives of this survey was to look at the special problems, if any, faced by caregivers who work outside the home. Results suggest that while working caregivers are no different with respect to service utilization and perceived needs, they do differ demographically and face different types of problems than those who are not employed.

Relative to others, working caregivers are more likely to be secondary, rather than primary caregivers. A larger number are men, who are younger, better educated and live in more affluent households. With respect to caregiving responsibilities, full-time employees bear a lighter load than part-time employees and those who were previously working. Full-time employees appear to care for "healthier" recipients. These recipients are most likely to be living in their own home and are least likely to be housebound. On average, caregivers who are working full-time spend less time per week on caregiving and perform fewer ADLs. (See charts on following page.)

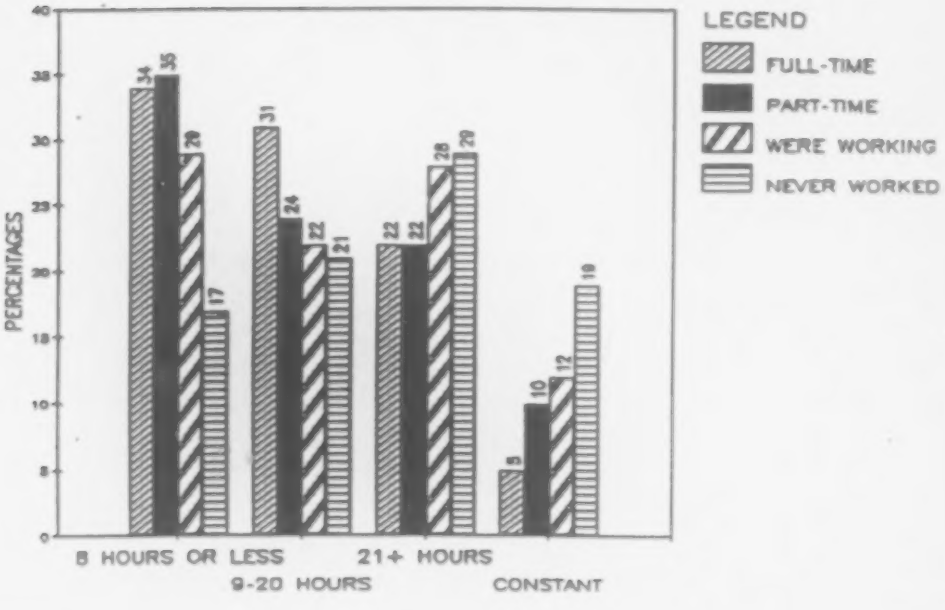
There is evidence to support the contention that caregiving duties may result in time lost from work. More than one-third (38%) of employed caregivers report a change in work status since becoming a caregivers; they have either lost time from work or have come in late as a result of their caregiving duties. From an economic standpoint, 20 percent of those who have reported some change in their work status have lost some benefits as a result.

As many as nine percent of working caregivers have taken a leave of absence, and six percent have cut down their hours from full-time to part-time. In fact, 14 percent of those who currently work part-time say they have had to cut down their hours strictly as a result of caregiving. Perhaps the hardest hit are those who previously worked, 15 percent of whom chose early retirement and 12 percent of whom had to give up working entirely as a result of caregiving.

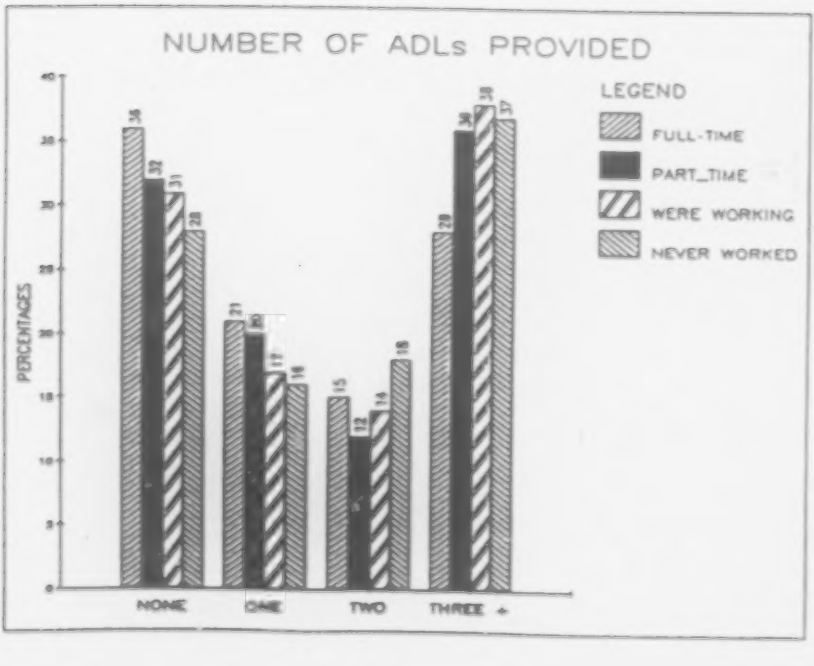
Caregiving also creates stresses in the workplace. A small number of working caregivers have had problems with their supervisors (4%) and three percent had to turn down a promotion as a result.

When taking all monthly expenditures into consideration, it is the previously employed caregivers and those who have never been employed spend the greatest percentage of their income on caregiving. While on average, all caregivers typically spend seven percent of their income on caregiving, individuals who previously worked report spending 15 percent of monthly income on caregiving for an average of $223 per month. This compares to expenses that are five percent of monthly income and average $107 among full-time employees.

HOURS PER WEEK SPENT ON CAREGIVING BY WORKING CAREGIVERS



NUMBER OF ADLs PROVIDED



CONCLUSIONS & IMPLICATIONS

This research represents the first attempt at a national survey examining the caregiving continuum. The results have important implications particularly for further research, educational efforts and public policy. Following are the questions and significant findings that emerge from this data.

Service Utilization

The research provides a snapshot view of the caregiving continuum. As the older person's needs increase, so does the need for more intensive caregiving. Also, it appears that caregivers do not perceive a strong need for services until their responsibilities reach crisis proportions.

Consequently, program planners may want to begin implementing strategies designed to raise public awareness about the caregiving issue emphasizing the need for and value of planning ahead. Planners may also want to make helpful information available to persons who have not used their services, emphasizing the value of some support before a crisis level situation develops. In addition, aggressive outreach efforts to identify the most overburdened caregivers who percieve a high need for all services would be appropriate.

Additional information is needed regarding the continuum of care and the point at which a caregiver reaches out for support. Further clarification is also needed regarding the "perception that caregivers don't need services." Specific research questions may include:

- What is the most effective way of getting information to caregivers?
- How can caregivers be persuaded to plan before a crisis occurs?
- Thirty-nine percent of caregivers said they need assistance dealing with the service bureaucracy. How can the service system be modified so that caregivers can obtain needed assistance?
- Twenty-eight percent of caregivers in this study are 35 years of age and younger. What effect does caregiving have on this group? As most researchers have assumed that caregivers are much older, there is a lack of data on younger persons in this situation.

Costs of Caregiving

The research presented here is one of the first attempts to investigate the economic implications of caregiving. Although the information reported must be interpreted cautiously because the financial data are based on estimates, it represents a first step. Further clarification is needed on the financial costs associated with caregiving. The current data, however, do raise some interesting questions for public and private policy.

Perhaps policy makers may want to take a look at how "dependent" is defined. As only 37 percent of caregivers in this study share a household with the older person, should place of residence be a criteria for dependent-care tax credits and other benefits? As many caregivers are making significant financial contributions toward the care of aging loved ones, should caregivers be compensated perhaps through a tax incentive or through an employer-sponsored benefit which would cover the older person? Again, further research is needed before these issues can be addressed.

Working Caregivers

In the area of employment and caregiving, clearly additional research is needed about the effects of caregiving on work particularly as it pertains to loss of benefits and time lost from work. As the number of working caregivers is expected to increase, it may be wise for companies to begin exploring how to assist employee caregivers in order to avoid disruptions in productivity.

Conclusions

There are many other issues related to caregiving that need to be explored. The current research serves as a beginning and sheds some light on several issues. Perhaps more importantly, it raises many critical questions for further research, public policy and program planners.

Caregiving is -- or will be -- a reality for most Americans. It affects our families, our workplaces and our communities. The assistance provided by caregivers has its rewards but it can also create burdens. It is hoped that this research and future efforts will help develop creative and effective private and public initiatives that truly support caregivers.

A National Survey of Caregivers

Working Caregivers Report

March 1989

Conducted By:

Opinion Research
Corporation
Washington, DC

Conducted For:

American Association
of Retired Persons
Washington, DC

and

The Travelers
Foundation
Hartford, CT

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Background

It is a well-documented fact that the older American population is growing at a rate surpassing any other age group, and this growth is expected to continue into the foreseeable future. In fact, the 75 and older age group is experiencing the most rapid increase. This group, sometimes referred to as the "frail elderly," is most likely to need personal care and assistance to maintain independence.

The care of an older loved one is typically provided by relatives and friends. These caregivers are involved in a variety of activities such as bathing, feeding, dressing, managing finances and performing household chores. And although most Americans give such care freely, caregiving can create physical, economic and emotional stresses.

For working persons, the challenge of caregiving may be even more demanding as they attempt to balance it with the demands of work. During the past several years, there has been increased attention paid to the plight of working caregivers. Corporations are beginning to understand that caregiving, like all other personal concerns, affects employees' ability to function at work.

In order to add to the growing body of knowledge about this subject, AARP, with support from its Women's Initiative, and the Older Americans Program of The Travelers Companies, contracted with Opinion Research Corporation to conduct a National Survey of Caregivers among U.S. telephone households in 1987. During December 1987, and January 1988, 754 telephone interviews were conducted nationally.

For purposes of the survey, a "caregiver" was defined as a person who provided unpaid assistance during calendar year 1987 to a second person, aged 50 or older. The caregiver must have provided, at a minimum, at least two IADL's (instrumental activities of daily living such as arranging transportation, managing finances, and household chores) *OR* one ADL (activity of daily living such as bathing, dressing and feeding). This definition was chosen to allow examination of people giving a moderate amount of care as well as people in an intensive care situation.

This report focuses on data about working caregivers derived from the National Survey of Caregivers. The National Survey estimates that seven million U.S. households contained caregivers in 1987 and that 55 percent of these households contained a working caregiver.

TABLE 1
Who Are Working Caregivers?

		Current Employment Status			
		Employed		Not Employed	
	TOTAL	FULL-TIME	PART-TIME	WERE WORKING*	NEVER WORKED
(Base)	(754)	(318)	(100)	(98)	(238)
Sex					
Male	25%	36%	19%	20%	14%
Female	75	64	81	80	85
Age					
Under 35	28%	36%	33%	32%	14%
35-49	29	37	33	26	19
50-64	26	26	23	21	29
65 +	15	1	8	20	35
Median Years	45	40	42	44	57
Marital Status					
Married	66%	65%	60%	64%	69%
Not Married	34	34	39	35	31
Education					
High School Incomplete	17%	7%	25%	16%	26%
High School Degree	38	41	29	44	36
Some College	21	21	27	25	16
College Degree Plus	21	29	17	13	10
Respondent Occupation					
White Collar—Professional	25%	48%	32%	3%	3%
Retired	16	0	2	31	37
Homemaker	15	1	2	25	37
White Collar—Sales	13	20	25	5	1
Blue Collar	13	21	22	4	2
Service Worker	6	9	13	3	**
Not Employed	11	0	0	29	21
1986 Household Income					
Under $10,000	11%	5%	14%	23%	13%
$10,000-$19,999	17	18	12	17	19
$20,000-$24,999	9	10	12	10	5
$25,000-$34,999	19	25	16	13	14
$35,000-$49,999	14	16	14	15	9
$50,000 or more	10	14	12	4	7
Don't Know/Refused	13	7	14	7	23
Median	$26,100	$29,800	$25,800	$20,400	$20,900
Race					
White	85%	79%	86%	90%	89%
Black	11	15	10	5	8
Other	5	6	4	5	3
Primary Caregiver					
Yes	63%	57%	57%	60%	75%
No	33	38	42	32	22

**Persons who were employed while caregiving, but who were not employed during the interview.*

***Denotes less than 0.5%.*

Working Caregiver Profile

Table 1 compares demographic characteristics of employed caregivers with caregivers who are not employed. Employed caregivers do differ demographically from those who are not employed. They are more likely than others to be younger, male, and college-educated. They are also more likely to live in more affluent households and have *secondary* rather than *primary* responsibilities for their older loved ones.

TABLE 2
Caregiving Responsibilities of the Working Caregiver

	Current Employment Status	
	FULL-TIME	PART-TIME
(Base)	(318)	(100)
Hours Per Week		
8 hours or less	34%	35%
9-20 hours	31	24
21 or more hours	22	22
Constant Care	5	10
Median Hours	10	10
Type of ADLs Provided	%	%
Walk around inside using wheelchair, etc.	44	52
Dress/undress	33	41
Bathe	34	36
Use the toilet	26	34
Feeding	24	29
None	36	32
Number of ADLs Provided		
None	36%	32%
One	21	20
Two	15	12
Three +	28	36
IADLs Provided	%	%
Grocery Shopping	82	78
Transportation	81	78
Housework	75	72
Preparing meals	64	67
Managing Finances	66	58
Administering Medicine	42	38
None	1	3

Caregiving Responsibilities

Working caregivers spend about ten hours weekly on caregiving (See Table 2). Thirty-four percent of full-time workers and 35 percent of part-time workers give care eight hours or less. Twenty-seven percent of full-time workers and 32 percent of part-time workers spend 21 or more hours per week on caregiving. Thus, many employees are "working" a job and a half when taking caregiving and employment responsibilities into account.

Most employed caregivers provide assistance with instrumental activities of daily living (IADLs). The most frequent

	Current Employment Status	
	FULL-TIME	PART-TIME
(Base)	(318)	(100)
Relationship to Caregiver		
Mother	31%	25%
Father	14	13
Parent—In Law	14	8
Spouse	3	6
Grandparent	19	20
Other Relative	8	17
Non-Relative	13	21
Distance		
Same Household	29%	35%
Within 20 minutes	53	49
20 minutes or more	13	16
Living Arrangement		
Same Household	29%	35%
Own House/Apartment	55	51
Nursing Home	6	4
Other	10	10
Type of Disability		
Physical	71%	74%
Mental	3	4
Both	21	21
Condition Severity		
Acute or short-term	17%	15%
Chronic or long-term	68	69
Both	6	3
Housebound		
Yes	52%	65%
No	48	35
Bedridden*		
Yes	29%	28%
No	70	72
Wheelchair-Bound*		
Yes	21%	28%
No	79	72
Age		
50-64	12%	12%
65-74	26	31
75-84	40	28
85 or Older	20	26
Median Years	77	78

TABLE 3
Who Are Care Receivers of Working Caregivers?

*Base = those who are housebound

IADL assistance provided is grocery shopping, transportation, and housework. Over 60 percent of caregivers also provide assistance with activities of daily living (ADL's). And, 28 percent of full-time workers and 36 percent of part-time workers provide assistance with three ADL's.

Care Receiver Information

Table 3 provides information on the care receivers. Full-time workers are most frequently caring for their mother (31%), grandparent (19%), father (14%), or parent-in-law (14%). Twenty-nine percent live with their older loved one while 13 percent live 20 minutes or more away. A chronic physical disability was listed by most full-time workers as the reason why care is needed. In fact, 52 percent of care receivers are housebound. The average age of the care receiver is 77.

Care receivers of part-time workers differ little from full-time workers. One noticeable difference is that part-time employees are more likely to care for a mother (25%), non-relative (21%), or grandparent (20%). Part-time workers also care for older persons with greater limitations since 65% of their care receivers are housebound.

Changes In Work

Providing caregiving assistance can be particularly stressful for working caregivers and may affect time spent at work. Table 4 shows the changes in work for currently employed caregivers. Fully one-third of employed caregivers report that they have lost time from work or have come in late as a result of their duties.

Employed caregivers also have made other significant changes in work activities. Nine percent of full-time employees and seven percent of part-time employees say they had to take a leave of absence. Among part-time workers, 14 percent say they had to go from working full-time to part-time. Perhaps the hardest hit are those who previously worked (98). 15 percent of whom chose early retirement and 12 percent of whom report that they had to give up working entirely.

There also is evidence that caregiving creates additional stresses in the workplace. A small number report either having had problems with their supervisor because of their outside responsibilities or having had to turn down a promotion

TABLE 4
Changes in Work

	Current Employment Status	
	FULL-TIME	PART-TIME
(Base)	(318)	(100)
Lose time from work, such as coming in late, taking time off, etc.	33	37
Choose early retirement	N/A	N/A
Have to give up working entirely	N/A	N/A
Have to take a leave of absence	9	7
Have to go from working full-time to part-time	4	14
Have problems at work with your supervisor because of these caregiver responsibilities	4	4
Have to turn down a promotion	3	5
None	34	35

TABLE 5
Expenses Incurred While Caregiving by Working Caregivers

	Current Employment Status	
	Employed	
	FULL-TIME	PART-TIME
(Base)	(318)	(100)
Expense	%	%
Travel related to providing assistance	39	27
Telephone bills to keep in touch	26	24
Special diets or medicines	24	25
Doctors' fees	15	11
Special changes to your own home or your *(relationship's)* home	17	8
Purchasing/renting medical equipment	14	12
Homemaker or cleaning services	14	10
Hospital care	9	9
Home health aides	12	7
Respite care	9	5
In-home nursing care	5	4
Food	5	2
Adult day care	3	0
Clothing (diapers)	2	2
Household Utilities	1	2
Other	7	6
None	37	43

Caregiving Expenses

Caregivers were provided with a list of items and were asked if they *personally* had to pay for this kind of expense or not. Sixty percent of all caregivers incurred additional expenses as a result of giving care. Table 5 reports on the percentage of working caregivers incurring specific expenses. The most frequently reported expenses were travel, telephone bills and special diets or medicines. Expenses related to keeping in touch are not what one [illegible] thinks of when thinking [illegible] caregiving expenditures. Expenses such as respite [illegible] home nursing and adult [illegible] care were incurred by [illegible] caregivers. The most [illegible] incurred expenditures [illegible] were not the most [illegible]. Table 6 examines the [illegible] monthly expenditures [illegible] working caregivers. Full- [illegible] and part-time workers [illegible] the most expensive [illegible]

	Current Employment Status	
	Employed	
	FULL-TIME	PART-TIME
Expense	$	$
Hospital Care	167	245
In-home nursing care	475	488
Respite care	75	400
Homemaker or cleaning services	65	100
Adult day care	70	0
Home health aides	55	138
Special diets or medicine	44	55
Doctor's fees	47	39
Food	38	25
Clothing	40	60
Household utilities	33	275
Travel related to providing assistance	29	38
Telephone bills for keeping in touch	25	23
Other	113	150

TABLE 6
Average Monthly Caregiving Expenditures by Working Caregivers

expenditures. Full-time workers average $475 per month on in-home nursing, $167 per month on hospital care and $113 on other expenses. For part-time workers, the highest monthly expenses were $488 for in-home nursing, $400 for respite care and $275 for utilities.

Full-time employees use about five percent of their monthly incomes ($107) to pay for care-related expenses. Part-time employees incur additional expenses less often then full-time employees; however, when they do incur expenses, they are hit harder.

Conclusions

This research represents one of the first attempts to study the caregiving continuum, and is thus an ambitious undertaking to examine the effects of caregiving on time spent at work. Although additional research is clearly needed, this report is a first step toward providing national data on several issues frequently overlooked by researchers.

It is significant that 55 percent of caregivers are employed outside the home. This figure will increase during the years to come for several reasons. First, individuals over age 75 are the fastest growing segment of our population. These are the people who are most likely to need caregiving. Also, it is expected that women, the traditional caregivers, will continue entering the labor force in unprecedented numbers. And finally, more men and younger people are beginning to get involved in caregiving.

In the current study, 36 percent of caregivers were men and 36% were under age 35. These factors suggest that most workers are likely to find themselves in a caregiving situation at some point during their work history.

Working caregivers are spending an average of ten hours weekly on caregiving. Many workers are caring for housebound loved ones suffering from chronic conditions. Many of these caregivers probably hold demanding jobs that require long hours and possibly some travel. Thus, it is often stressful for employees to balance work and caregiving.

Caregiving does affect time spent at work. Often, lost time is caused by emergency situa-

tions or the need to connect with service organizations that normally operate on nine-to-five schedules. Further research is needed to document the effects of caregiving on worker productivity and loss of benefits caused by job status changes. Also, additional research is needed on the decision-making process for leaving the job market temporarily and/or permanently.

Many caregivers are incurring out-of-pocket expenses for care-related activities, services and equipment. The majority of these expenses are not reimbursable through federal or state programs. Again, further clarification is needed on financial costs associated with caregiving.

Caregiving is—or will be—a reality for most Americans. It affects our families, our communities and our businesses. This survey sheds some light on many issues related to working caregivers. Perhaps more importantly, it raises many critical questions for further research about how businesses might best respond.

It is apparent, however, that it would be wise for businesses to begin exploring how caregiving is affecting their employee population. After examining the needs of employees, businesses may then want to develop supports to meet the identified needs. Businesses will need to be creative in developing inexpensive, effective supports. This challenge is not so difficult if the private and public sectors cooperate to lessen the burdens caregivers face.

The Women's Initiative is the major effort of the American Association of Retired Persons to strengthen and enlarge the leadership roles held by women; to address the special health, financial, and social needs of middle life and older women; to create additional opportunities for women to realize their full potential; and to focus attention on the contributions women are making to society.

Because women are most often the caregivers, and because the majority of employees in institutions and agencies providing long-term care services are women, AARP's long-term care efforts are the responsibility of the Women's Initiative.

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CORPORATE AND EMPLOYEE RESPONSE TO CARING FOR THE ELDERLY

A NATIONAL SURVEY OF
U.S. COMPANIES AND
THE WORKFORCE

SPONSORED BY
FORTUNE MAGAZINE
AND JOHN HANCOCK
FINANCIAL SERVICES

1989

SUMMARY

INTRODUCTION

The purpose of this research was to assess how corporate America is responding to the demands of elder caregiving. Today there are approximately 30 million elderly persons in the United States, representing more than 12% of the population. By the year 2030 it is projected that there will be 65 million elderly people or 21% of the American population. With this rapid expansion of the elderly population in our country, we can anticipate that increasing numbers of employees will be faced with the responsibilities of working and taking care of an elderly relative or friend at the same time. Since providing care for aged relatives or friends can often be an emotional and financial drain on employees, the American business community can expect to be directly affected in terms of decreased productivity and quality of job performance. Some companies are beginning to think about ways in which they can assist employees who are coping with elder care responsibilities. In fact, the Conference Board describes elder care as the emerging employee benefit of the 1990's.

To assess how corporate executives and employees in America are dealing with the elder care issue as we enter the 1990's, FORTUNE Magazine and John Hancock Financial Services undertook this research endeavor as part of a mutual commitment and interest in examining critical issues affecting business and the workplace. It is hoped that this survey will provide American companies with information about the potential impact of employee elder caregiving in the workplace and with some of the options that are now available to plan and deal with the needs of the elderly and with the employees taking care of them.

METHOD

This research was based on mail questionnaires that were sent out to two populations: 1) Chief Executive Officers (CEOs) of the 1000 largest industrial and service corporations in the United States; and 2) a nationwide sample of the general population.

The corporate survey was directed to the CEOs of companies in the FORTUNE 500 Industrial listing and FORTUNE 500 Service listing. If CEOs were not able to fill out the survey, another executive was permitted to complete it. As it turned out, 91% of those who completed questionnaires were top management, including 58% who were CEOs, Chairmen, or Presidents.

The general population survey was mailed to heads of households. Although questions were directed to all adults in the general population, the findings reported herein focus on the employed population.

In order to foster cooperation, the survey packet included a cover letter from the publisher of FORTUNE Magazine, a stamped reply envelope and an incentive -- $5 for the CEOs and $1 for the general population. Only CEOs were sent a postcard to request a copy of the results of the completed survey. In addition, a second mailing to corporate executives was sent out several weeks after the initial questionnaire. The respondents were assured that their answers would be kept confidential and anonymous. All field work and tabulations were carried out by Pulse On America, an independent research firm located in New York.

Two different 8-page questionnaires were used -- one for the CEOs and one for the general population. The two questionnaires contained many of the same question areas, although approximately one-third of each questionnaire contained question areas not covered in the other.

In developing the questionnaires, valuable input was received from an advisory panel consisting of representatives from corporations, government agencies, and organizations dedicated to the problems of the elderly. (A list of the participating organizations is contained in Appendix C.) The final questionnaire and this report, however, are solely the responsibility of FORTUNE Magazine and John Hancock Financial Services.

A total of 1,000 questionnaires were mailed out for the corporate survey. Of those, 996 questionnaires were deliverable. And of the deliverables, 371 usable questionnaires were completed and returned. This represents a completion rate (usables as a percent of deliverables) of 37%, particularly high for such a notable group.

A total of 2,000 questionnaires were mailed out to the general population. Of those, 1898 (95%) questionnaires were deliverable. And of the deliverables, 581 usable questionnaires were completed and returned to us. This represents a completion rate (usables as a percent of deliverables) of 31%. The somewhat modest return rate for the general population suggests that responses may have come from adults who have an above-average concern about taking care of elderly people. If that is the

case, the level of personal concern with the issue of employees taking care of elderly relatives or friends reported in this investigation might be somewhat overstated. However, the level of concern expressed by employees in this survey concurs with the findings of other surveys.

The questionnaires for the initial corporate survey were mailed out November 18, 1988 and the second mailing for the corporate survey was sent out on December 29, 1988. The cut-off date for corporate responses was January 17, 1989. The questionnaires for the general population survey were mailed out November 25, 1988 and the cut-off date was January 10, 1989.

The data from both the corporate and general population surveys have a five percentage point margin of error due to sampling.

The Appendices contain a copy of the mailing materials and additional detail on the methodology employed in this investigation.

EXECUTIVE SUMMARY

This section presents the highlights of how businesses and employees are responding to caring for the elderly.

Corporate Concern And Understanding Of Elder Health Care Issues

- Health care costs (85%) is the number one problem facing American business today according to the corporate executives surveyed. This problem leads 15 other listed problems such as corporate concern about productivity (71%), improving the quality of the workforce (55%), drug/alcohol abuse (36%), foreign competition (22%), child care (19%), and AIDS (15%). It must be remembered, however, that executives were aware that they were filling out a questionnaire about caring for the elderly.

- The vast majority (89%) of corporate executives consider health care for the elderly to be a major problem in the United States. This viewpoint is similarly held by the employees surveyed (94%).

- Both corporate executives and the general population were tested on their knowledge of the issues and facts concerning health care for the elderly. Corporate executives are fairly knowledgeable about issues focusing on nursing home costs and the growing numbers of employees who are taking care of the elderly.

  On a variety of other elder health care issues, the corporate executives surveyed are only fairly knowledgeable and for the most part exhibit a fair amount of uncertainty. The issues where there is division and confusion include whether most nursing home residents are forced into welfare in the first year, whether the fastest growing segment in America are those over 85, whether people have to spend all or almost all of their assets to qualify for Medicaid benefits, and whether only a minority of elderly people will ever spend time in a nursing home during their lifetime.

  Employees, in comparison to corporate executives, are less knowledgeable about the current state of affairs regarding elder health care in the United States today.

- The largest share of corporate executives believe that individual citizens should be the ones most responsible for costs associated with long-term care for the elderly (48%). Fewer executives believe that the Federal government should be responsible (35%), and even fewer believe the corporate sector should be responsible (17%).

Unlike executives, employees are most likely to believe that the Federal government (41%) and less likely to think that individuals (33%) should take responsibility for the costs of long-term care needs. Employees, like executives, are least likely to think that employers should pay the costs (26%).

Personal Experience Taking Care Of The Elderly

- Corporate executives are not immune to the problems of elder care. The vast majority of corporate executives (89%) know someone who has taken care of an elderly person now or in the past two years, and half of the corporate executives (49%) are personally responsible for an elderly person now or have been in the past two years.

  Employees, like corporate executives, are very likely to know someone taking care of an elderly person (80%). Relative to executives, fewer employees (37%) are likely to be elder caregivers now or over the past two years. This finding is not surprising considering that the corporate executives surveyed are older on average than the employees surveyed (average age of 53.4 years vs. 38.5 years, respectively).

The Nature Of Elder Caregiving Responsibilities

- Employees with elder care responsibilities were probed in greater detail than corporate executives about their experiences taking care of elderly people. The following findings were disclosed:

  -- Four out of ten elder caregiving employees (41%) report that they are the ones mainly responsible for taking care of their elderly.

  -- The majority of caregiving is for parents (58%) and parents-in-law (27%).

  -- There are a variety of problems from which the elderly suffer: cancer (18%), depression (14%), death of a spouse (12%), stroke (11%), Alzheimer's (10%), old age (9%) and loneliness (3%).

  -- On average, employees have been providing care for their elders for four years.

  -- Caregiving to the elderly averages 13 hours per week for the employees surveyed.

  -- The most frequently cited responsibilities are transportation (59%), companionship (58%), and telephoning to offer emotional support (56%). Close to one-half (47%) also assume shopping, laundry and other household chores for the elderly people they look after. A wide variety of other responsibilities are also mentioned.

- Elder caregiving employees are two times less likely to turn to a supervisor than a co-worker (28% vs. 59%, respectively) for support in dealing with their caregiving responsibilities. Greater efforts at educating managers about the problems associated with elder caregiving employees might be beneficial.

Corporate Concern About Employee Elder Caregiving And Its Effects On The Workplace

- A surprisingly large one-half (48%) of the corporate executives surveyed indicate that they would be concerned about performing their own jobs and taking care of their elderly at the same time (if and when the need arose). Interestingly, they are more likely to think they are concerned than their company management (35%), and they are even more likely to think their employees are concerned (66%).

  Employees, as corporate executives might expect, are more likely to think that they (87%) and other employees (53%) are concerned about performing their jobs and taking care of their elderly than their company management (26%). As the findings point out, company management is not often believed to be responsive to the employee elder caregiving problem.

Perceived Extent Of Employee Elder Caregiving

- Corporate executives estimate on average that about three out of ten employees (27%) are currently working and taking care of elderly people. In fact, about one-quarter of employees (24%) in this investigation report that they now have responsibility for elderly relatives or friends. Since other current research indicates that between 25% and 40% of employees in America are elder caregivers, it appears that corporate executives have fairly accurate perceptions about this growing phenomenon.

Work-Related Problems With Employees Taking Care Of The Elderly

- Corporate executives are cognizant of the effect that employee elder caregiving is having on the workplace. Six out of ten (60%) executives are aware of specific work-related problems. The predominant problems which corporate executives have noticed are employee stress (45%), unscheduled days off (38%), late arrivals and early departures (37%), above-average use of the telephone (32%), and absenteeism (30%). Those in service companies are more likely than those in industrial companies to report having these problems.

- Employees with elder care responsibilities were also most likely to report emotional stress (51%) as a work-related problem associated with caregiving. Employees were also likely to mention that above-average use of the telephone (44%) and time off for emergencies (44%) are problems which they have experienced. Female employees and lower-income employees are more likely to report stress and anxiety as side-effects of elder caregiving than male employees and higher-income employees.

- In accordance with the high stress-related nature of simultaneously working and caregiving to the elderly, the vast majority of employees (70%) state that it is "very difficult" to be an employed elder caregiver and 77% state that taking care of elderly relatives or friends interferes with their jobs.

Women Employees And Elder Caregiving

- Despite the fact that so many of the predominantly male executives surveyed have experience taking care of the elderly, elder caregiving is still more often viewed as a female issue than a male issue by executives at the top (64% vs. 3%, respectively).

- There is much truth to executives' perceptions of the female role in providing care to the elderly.

  Female employees are more likely than male employees to have personal responsibility now or in the past two years for caring for the elderly (43% vs. 32%, respectively); to name themselves as the main providers of care (49% vs. 32%, respectively); to spend more hours per week in caregiving on average (15.4 hours vs. 10.0 hours, respectively); and to provide a wider variety of tasks related to caring for the elderly. Of interest, women are more likely than men in the workplace to provide direct support such as companionship (66% vs. 51%, respectively), personal care needs (34% vs. 9%, respectively) and administration of medicine (30% vs. 14%, respectively). Men are more likely than women in the workplace to offer indirect support to their elderly parents or friends by telephoning to offer reassurance (62% vs. 50%, respectively).

- If confronted with the situation, female employees are more apt than male employees (61% vs. 52%, respectively) to anticipate quitting their jobs or taking time off from work to help take care of their elderly. Women are more likely than men in the workforce today to expect that they would take a long period of time off from work (29% vs. 11%) to deal with this problem. This finding for female employees raises some important questions if women will be dropping in and out of the workforce just when they are reaching the peak of their careers and are most useful to corporate America. It appears that business in the United States might be considerably disrupted in the years to come, particularly in light of the shrinkage in the well-educated labor pool.

Corporate Responsibility For Employees' Family Problems

- The majority of corporate executives and employees (80% and 84%, respectively) agree with the statement that "employers should establish policies or programs that enable employees to deal with family issues that impact on work performance." Executives representing service companies and non-unionized companies are more strongly in agreement with this statement than those in industrial companies and unionized companies.

Company Policies For Helping Employees Take Care Of The Elderly

- Corporate executives were asked about the kinds of company policies or programs that are currently available to help employees deal with taking care of elderly relatives or friends. The most often mentioned benefits available to employees are personal days off (67%), health benefits coverage for family members (63%), unpaid leaves of absence (61%) and sick days (60%).

  Policies that are designed specifically to meet the employee elder care problem are less widespread. Employee assistance programs (EAP) that offer elder care service guidance (39%), information and referral on elderly services (26%), and flexible benefit plans with Dependent Care Assistance (DCAP -- 18%) are less widely available.

  Service companies are more likely than industrial companies and non-unionized companies are more likely than unionized companies to offer policies and programs to assist employees with elder care responsibilities.

- Employees are considerably less knowledgeable about company policies or programs that are available to assist them with taking care of their elderly than are corporate executives. Like corporate executives, they most often cite the more commonly available programs and policies such as health benefits coverage (55%), sick days (54%), personal days (47%), and unpaid leaves of absence (47%).

- The most often mentioned company policy directly tied to elder caregiving and mentioned by executives is company contributions to community aging programs (53%). Interestingly, only one-fifth (20%) of employees in larger companies mention this policy. It would perhaps be beneficial to corporations to better publicize this activity.

Company Policies Being Actively Considered
To Help Employees Take Care Of The Elderly

- There appears to be some movement towards offering more services for employees with elder care problems. The company policies or programs which corporate executives indicate that they are actively considering include flexible benefit plans with DCAP (18%), information and referral on elderly services (16%), articles in employee newsletters (13%), and employee seminars or educational programs (13%).

Corporate Familiarity With Long-Term Care Insurance

- Corporate understanding of long-term care insurance and the factors encouraging and discouraging its adoption in companies today were probed. In addition, corporate executives were asked about their likelihood of offering this benefit to employees under a variety of financial conditions.

The concept of long-term care coverage was defined to corporate executives and employees in the questionnaires and the cost of this coverage was estimated at about $200 per employee per year when provided through the company.

Overall, only about one-third (34%) of the corporate executives surveyed report that they are familiar with the features of long-term care coverage. In fact, only a minority (10%) indicate being "very" familiar with this coverage. Employees are far less knowledgeable about this benefit (5%).

Current And Anticipated Provision Of Long-Term Care Coverage

- A small number of corporate executives and employees (8% and 7%, respectively) report that their companies currently offer long-term care insurance coverage. Even these small proportions are an exaggeration, however, since only a handful of companies across America currently offer long-term care coverage. There must be some confusion over what long-term care coverage really is; executives and employees seem to be confusing their medical care benefits with long-term care coverage.

- A sizeable 18% of the corporate executives surveyed indicate that their companies are currently investigating the option of providing long-term care coverage.

- The few corporate executives and employees who indicate that they have company-provided long-term care coverage are most apt to believe that the costs for this benefit are shared between employer and employee (53% for executives and 57% for employees). Again, there is evidence of confusion with medical coverage since long-term care coverage is entirely employee-paid at this time.

Factors Promoting The Provision Of Long-Term Care Coverage

- The corporate executives indicating that they have long-term care coverage (30 companies) most often cite top management interest (60%), interest on the part of the benefits department (57%), part of an overall benefits evaluation process (47%), and employee requests (40%) as the factors motivating the acquisition of long-term care coverage. Thus, corporate executives see themselves as playing a central role in affecting their company's interest in this benefit area.

- Employees, like corporate executives, most often cite employee requests (45%) and interest on the part of top management (41%) as the factors which would motivate companies to provide this benefit.

Factors Preventing Companies From Offering Long-Term Care Coverage

- Among corporate executives, the leading barriers to offering long-term care coverage are fear of government mandates for employer contributions to the plan (40%) and unfavorable tax

treatment (37%). Other perceived obstacles are lack of employee interest (23%), employer's administrative costs (23%), non-availability of long-term care coverage plans (22%), and fear of employee pressure for employer contributions to the plan (20%). Top executives appear to think that they will not be treated fairly by the government or their employees if they adopt long-term care coverage for their workforce.

Amount Would Be Willing To Pay For Long-Term Care Coverage

- When asked which of several methods of payment for long-term care coverage is preferable, corporate executives and employees are somewhat divided in their preferences.

  The greatest consensus would be reached by company-provided coverage that is paid for totally by the employee. Nearly six in ten (62%) corporate executives and four in ten employees (43%) report that they would be interested in long-term care coverage in the next five years if it was entirely paid for by employees at a reduced rate through their companies.

  The second closest consensus would be reached by sharing the costs of coverage. One-third (33%) of the corporate executives surveyed report that their companies would be likely to offer long-term care coverage for employees if the costs were shared, while over one-half (58%) of employees surveyed would be willing to acquire this benefit under these terms. Although employees are most interested in the employer paying totally for the coverage (66%), this option is not really viable from an employer's point of view -- only 3% of corporate executives would be willing.

- Both corporate executives and employees were asked to indicate how much money they thought their companies and the average employee would be willing to pay towards long-term care coverage if it were shared. Using an average of $200 per annual premium per employee, corporate executives and employees were remarkably similar in their estimates of what the respective parties would be willing to pay. Both corporate executives and employees estimate that the average employee would be willing to split the premium just about in half with their company ($104 and $94, respectively). Corporate executives and employees estimate that their companies would only be willing to contribute less than one-fifth of the cost ($43 and $27, respectively).

ADDITIONAL INFORMATION

Detail on the findings presented in this summary as well as other findings from the research are provided in the full report of the study. A copy of this report can be ordered by writing to:

Dr. Leslie Gaines-Ross
Associate Director of Market Research
FORTUNE Magazine -- Room 1553
1271 Avenue of the Americas
New York, NY 10020

Please be sure to specify that you would like a copy of the full report.

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FOR IMMEDIATE RELEASE
October 15, 1987

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GREATER DEMANDS ON CAREGIVERS OF FRAIL ELDERLY ANTICIPATED

Washington, D.C.--In 1982, approximately 2.2 million caregivers aged 14 or older were providing unpaid assistance to 1.6 million noninstitutionalized elderly persons unable to perform one or more basic activities of living, such as dressing or bathing. A recent study, published in the October issue of THE GERONTOLOGIST, presents the first national profile of these caregivers, and raises questions about the capacity of informal helpers to continue providing the bulk of frail elders' long-term care.

The study, headed by Dr. Robyn Stone of the National Center for Health Services Research and Health Care Technology Assessment, is based on data from the 1982 Long-Term Care Survey, and substantiates many findings from studies of smaller nonrepresentative samples of informal caregivers. Due to longer life expectancy and delayed childbearing, for example, an increasing proportion of women will be in the position of providing care to both children under the age of 18 as well as elderly parents. These social trends, coupled with the projected increase in labor force participation rates among older women, imply that work and family obligations may conflict with caregiving responsibilities to a greater extent than they do today. About half of the caregivers included in Dr. Stone's national profile reported child care or work responsibilities that were difficult to handle while also caring for a frail elder: 9 percent indicated that they had quit their jobs.

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NEWS

The study also confirms the findings of previous studies which have documented the low use of formal, i.e., paid, care by caregivers. The analyses indicated that caregivers tended to provide care alone or with assistance from unpaid helpers. Less than 10 percent reported the use of paid services, and those who did rely on formal care were assisting the most severly impaired elders. This finding supports the observations of other researchers that formal care is viewed as a last resort when the responsibilities become too complex to handle alone or with unpaid assistance.

Finally, this national profile confirms that most informal caregivers are female, usually wives or daughters of frail elders. Husbands, however, comprised 13 percent of the informal caregivers and were found to be among the oldest of the caregivers. Moreover, about one-half of the men provided care with no additional informal assistance.

The researchers note the relevance of these data for policymakers examing the implications of various policy options. For example, they state that policymakers "might use these national estimates to ascertain how many caregivers would be eligible for the Child and Dependent Care Tax Credit under alternative sets of criteria. Similarly, decision makers in the private sector could use the estimates on work conflict to support the development of new programs targeted to employed caregivers."

Other members of the research team are Gail Lee Cafferta, National Center for Health Services Research and Health Care Technology Asssessment, and Judith Sangl, Health Care Financing Administration.

THE GERONTOLOGIST is a refereed journal published by The Gerontological Society of America.

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Author
p. 109

OLDER WOMEN'S LEAGUE

FAILING AMERICA'S CAREGIVERS:

A Status Report on Women Who Care

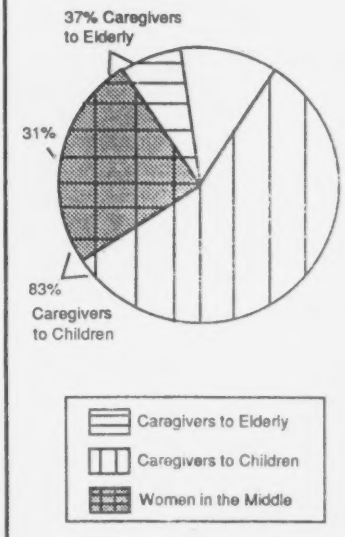
If you are a woman, you can expect to spend 18 years of your life helping an aging parent and 17 years caring for children—and the economic, physical, and emotional price may be high. Eighty-nine percent of all women over age 18 will be caregivers either of children or parents, or both, in their lives. Nearly four out of every ten women (37%) will care for a disabled adult, while 83% will care for children.

Caregiving to the young and old has far-ranging consequences. While policy-makers have begun to focus on the caregiving problems parents face, they have virtually ignored the ever-increasing need for elder care support.

The "empty nest" left when children are grown is more and more often being filled with an aging parent who needs long-term care. As the population ages and as more women enter the labor force, the immense need for greater child care and elder care options will only grow more urgent.

Many of the same problems associated with parenting exist for caregivers to the elderly. While child care is expensive, elder care impoverishes. The tragic results of poor quality care are far too commonplace for both young and old. Child care has been the work and family conflict of the '80s, but demographics foreshadow elder care as the number one work place issue of the 1990s. And sleepless nights are the same whether caused by a sick child or an elder parent.

Percent Of Women Over 18 Who Will Be Caregivers During Their Lifetime



Sources: The data to compile this statistic were drawn from: Bureau of the Census, Projections of the Population of the United States by Age, Sex, and Race: 1988 to 2080, Series P-25, Table P; Bureau of the Census, Statistical Abstract of the United States: 1988, Table No. 13, Total Population, by Age and Sex: 1960-1986; 1984 National Long-Term Care Survey.

There are up to seven million households caring for a disabled elderly person each year. Ninety-five percent of persons over 65 live at home. Even among the elderly who are disabled, 90% live at home, with family members providing practically all the care they receive. Without family caregivers, many more elderly would be forced into institutions. Yet family caregivers do their work largely without help, without resources, and without support.

Caregivers of the young and old devote enormous time and energy to their responsibilities. Like parenthood, elder care is an everyday responsibility: 80% of family caregivers to the elderly provide care seven days a week. One study estimates that caregivers to the elderly provide over 27 million days of unpaid care every week. One out of every five family caregivers to the elderly has been providing care for five years or more.

Caring for children and the elderly can be rewarding, but this report shows that for most caregivers, particularly of the elderly, the lack of support makes caregiving an act of love with grave consequences.

A Message From Lou Glasse, President of the Older Women's League

Happy Mother's Day! This is the weekend each year when Americans honor our mothers by sending chocolates, flowers, and cards to convey the gratitude we feel for the sacrifices they made for us when we were children.

But in truth, the sacrifices most women make are not limited to motherhood. A new body of data is emerging that documents the care women provide throughout their lives to children, parents, spouses, siblings, and other needy friends and relatives. Frankly, the facts are startling.

For the first time ever, American women are spending more years caring for dependent parents than for children—and millions spend additional time caring for frail or sick husbands, brothers, and other relatives.

In 1989, the "empty nest" is an anachronism. If women's "nests" empty at all, they fill again very quickly. Nearly two million women are part of the "sandwich" generation; they care simultaneously for growing children and ailing parents. Many more have only a brief respite between the time children move out and parents, aunts, uncles, siblings, or husbands require assistance.

The facts belie the stereotype that America's elderly are "warehoused" in nursing homes; only five percent are institutionalized. Nine in ten of the disabled elderly not in nursing homes receive unpaid care from relatives and friends.

Up to seven million Americans are unpaid caregivers to the elderly; the vast majority are women. Most toil without respite, doing backbreaking labor in virtual isolation. They routinely struggle to cope with the exhaustion, loneliness, brutal physical demands, and heartbreak of watching a loved one grow weaker. While children grow stronger and less dependent over time, frail or incapacitated adults most often grow only weaker and more dependent.

Our nation's health care cost containment policies are forcing patients out of hospitals quicker and sicker. These practices are increasing women's caregiving responsibilities at a time when more women are in the paid work force than ever before. More than half of the mothers of infants under a year old, and of the spouses and children of disabled elders, are in the paid work force. They face a massive, sometimes crippling responsibility from which there is often little relief. Many caregivers struggle to hold onto their jobs, but are finally forced to make an agonizing choice. For midlife and older women, the economic consequences of caregiving can be devastating.

Caregivers fill in the blanks in our health care system. When children are too sick to go to school or when parents are too weak to care for themselves, it is mothers and daughters who most often rearrange their lives to help out.

That must change. Midlife and older women cannot continue to bear almost the entire burden of providing care to increasing numbers of disabled seniors and dependent children. Men and women, young people and old, must also shoulder the responsibilities of family caregiving. But families alone cannot bear the full burden. Government and employers must do their share, too.

At present, America is failing its caregivers. Our health care system is woefully inadequate to meet the needs of an aging population. Finding child care slots is difficult for healthy children and impossible when children are sick. Services like home health care, respite care, and day care for children and adults can ease the burden on caregivers, but too often they are unavailable.

Legislation to provide more support services is urgently needed. The Family and Medical Leave Act to provide job protection for caregivers of children, parents, and spouses must be enacted. Long-term care for the chronically ill and increased wages, benefits, and training for long-term care workers are long overdue, as is increased funding for elder and child care services.

As in years past, this Mother's Day, the Older Women's League is issuing a challenge to America's policy-makers. Give your mother more than a hug and flowers. Show her you care, too. Give her a gift that can make her life better. Support America's caregivers. They have earned it!

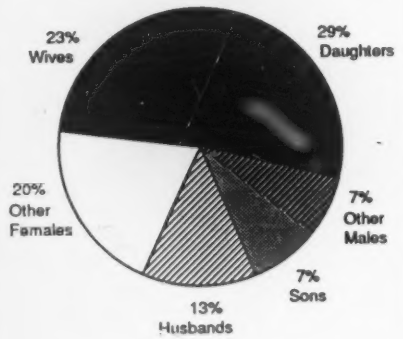
Who Are The Caregivers?

Women are. While men are assuming greater parenting and caregiving responsibilities than in the past, the paid and unpaid caregivers of the young and old are overwhelmingly female.

Originally, women may have been the caregivers because they were at home, but women's increased employment has not significantly diminished their caregiving role. Now, women simply do both. Women working full-time are four times as likely to be primary caregivers to the elderly than working men.

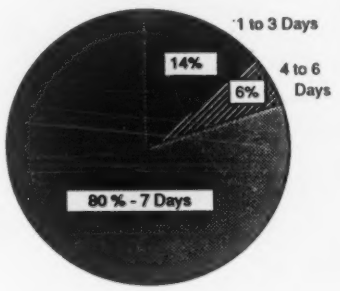
In responding to a national survey, nearly one in five caregivers reported she "chose" to take responsibility for the care of an elderly spouse, parent, or friend; one in three took on the job because she lived closest to the elderly person; and one in four reported she had no choice, as no one else was available or willing.

Caregivers' Relationship To Elderly Care Recipient



Source: 1982 Long-Term Care Survey/Informal Caregivers Survey

Days Each Week Spent Caregiving



Source: 1982 National Long-Term Survey/Survey of Caregivers

The vast majority of family caregivers are women. The average caregiver to the elderly is 45 years old, female, and married. Three out of every four caregivers to the elderly are women. Two-thirds are married. Among children who are primary caregivers, daughters outnumber sons three to one. Women provide most informal child care, with single parent families maintained by men accounting for only 3% of all families.

Thirty-five percent of caregivers to the elderly are over 65. Ten percent are over 75. As women outlive men and often marry older men, they often become caregivers to their spouses.

Many women in the "sandwich generation" have both elder care and child care responsibilities. Thirty-one percent of all women over 18 will care for both children and parents over their lifetime. Presently 1.8 million of these "women in the middle" are simultaneously caring for children while coping with elder care responsibilities. Over half are also in the paid labor force, and one in five has a parent living in her home.

Men are assuming more of a caregiving role, but most are providing help with transportation, home repairs, and financial management, rather than personal care. While no significant gender differences exist in the amount of time spent caregiving, the tasks performed are still very gender-based.

Living arrangements often must be changed to accommodate elder care needs. Almost three-quarters (74%) of caregivers live with the disabled elderly person; of these, 61% are their son or daughter. Over a third of caregivers report that they would not live with their parent if their assistance were not required.

Paid caregivers of adults and children are primarily women, earning low wages, with few benefits and little training. Over 95% of home health aides, 90% of nursing aides, and 94% of child care workers are women. Average wages range from $4.25/hr. for home health aides to $4.50/hr. for nursing aides. Ninety percent of child care workers providing care in their own homes, and 58% of all other child care workers, earn below poverty level wages. Less than 50% of nursing aides have health insurance, and less than one in five has pension coverage. Anecdotal reports show an even worse benefit picture for home health aides and child care workers. The women who bathe, feed, dress, and care for our parents and children earn less than zookeepers or parking lot attendants.

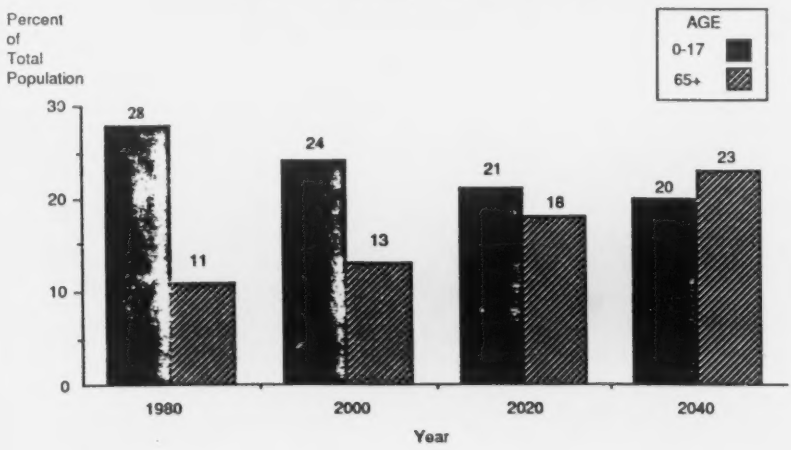
America's Increasing Need for Caregivers

A significant decline in the number of family caregivers will occur in the U.S. at the same time the demand for caregiving increases. As the population ages and life expectancy increases, there will be more elderly—especially 85 and over—with chronic illnesses. Since the baby boomers have created a baby bust by having fewer children, the ranks of future caregivers will be depleted. The U.S. population "pyramid" soon will become a rectangle.

Greater numbers of women will enter the work force and stay there, unlike their mothers who left to take care of their families. More women will be juggling work and caregiving responsibilities, therefore, and will need access to better-quality, lower-cost child and elder care than is presently available.

Americans 85 and older, the group most in need of long-term care, are the fastest growing segment of the population. By the year 2000, persons over 85 will increase from the current 2.9 million to 5 million. Between 1985 and 2020, the over-65 population will more than double to over 52 million, or one in six persons.

Children and Elderly as a Percentage of Total Population Actual and Projected, 1980-2040



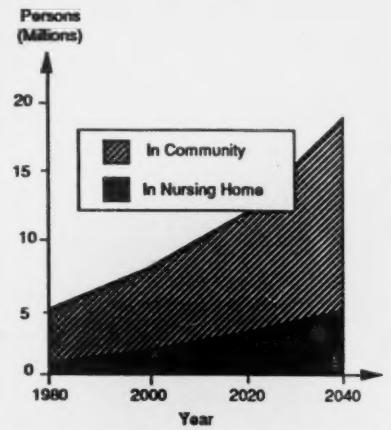
Source: Bureau of the Census, Projections of the Population of The United States by Age, Sex, and Race: 1988 to 2080, Series P-25, Table F, February 1989

Advances in medical technology have increased life expectancy, but living longer brings increased chances of illness and dependency. In 1986, the average life expectancy for women was 78.5 years and 71.5 years for men. By 2005, life expectancy will increase to 81 years for women and 74.1 for men. The incidence and impact of chronic illness increases with age. As chronic illnesses are "managed" rather than cured, they often require ongoing assistance and attention. In 1989, there were an estimated 7.1 million disabled elderly. By the year 2000, this number will increase to 8.9 million.

Fewer children will be available to care for the future generation of elderly. During the 1990s the total number of births will drop by 9.2%. Simultaneously, the elderly population will increase by over 10%. The number of elderly in the South and West will increase about 20%, with the greatest increases in Nevada (70%), Arizona (50%) and Florida (39%).

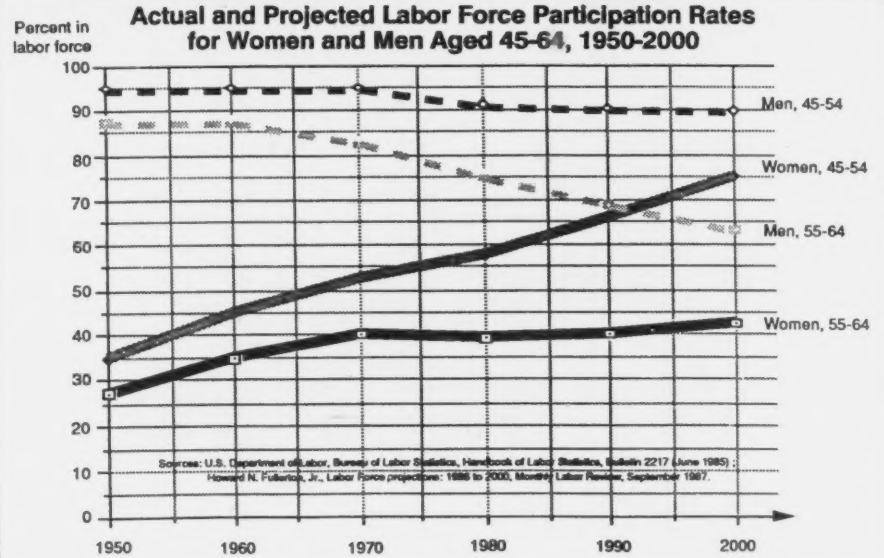
As more and more women enter the labor force, the need for affordable, quality elder and child care will increase. Fewer than one in ten families have a parent at home while the other parent works. Almost two-thirds of new employees in the next decade will be women, and by the year 2000 the work force will be 47% female. In 1970, 22 million working women had children under 18; by 1986 there were 37 million. Over half (52%) of all married mothers with infants under one year old are in the work force, as are over half the caregivers to the elderly (55%).

Older Americans Needing Long-Term Care, 1980-2040



Sources: Manton and Soldo, "Dynamics of Health Changes in the Oldest Old: New Perspectives and Evidence," Milbank Memorial Fund Quarterly, vol. 63, No. 2, Spring 1985 and unpublished tabulations from the author.

Actual and Projected Labor Force Participation Rates for Women and Men Aged 45-64, 1950-2000



Sources: U.S. Department of Labor, Bureau of Labor Statistics, Handbook of Labor Statistics, Bulletin 2217 (June 1985); Howard N. Fullerton, Jr., Labor force projections: 1986 to 2000, Monthly Labor Review, September 1987.

What's A Family To Do?

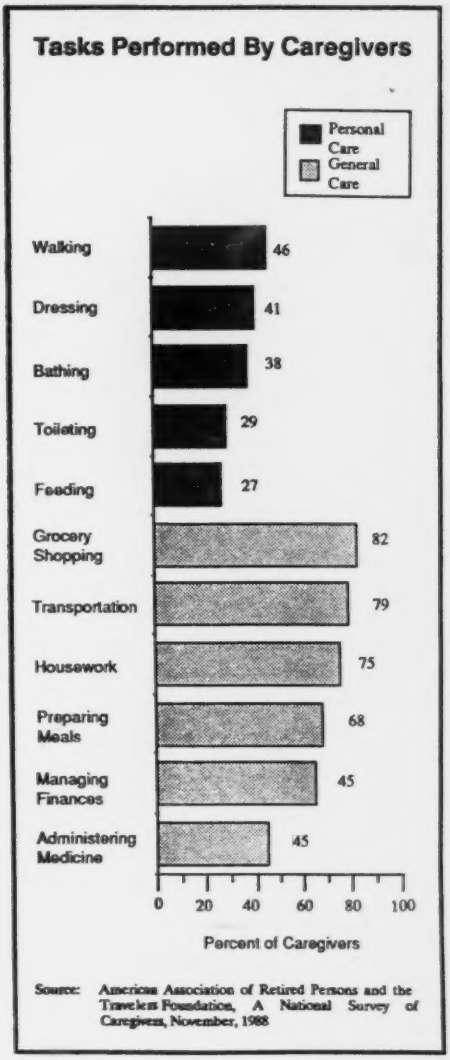
At present, few options exist for families with elder care or child care responsibilities. Most families are dual earning or single parent, leaving no one at home to provide full-time care. Older, retired caregivers urgently need assistance with the physical and emotional demands of elder care. Unfortunately, very little outside help is available either for elder or child care. That which does exist is expensive, of poor quality, or both.

Nursing homes—a question of cost, space, and quality. Median family income of the elderly is about $20,000 a year; the average annual cost of staying in a nursing home is $25,000. Many cost up to $50,000 a year. In almost every state occupancy rates in nursing homes average well over 90%. Discrimination against the poor is rampant in the competition for limited slots. Despite the high cost and limited supply, quality of care remains in doubt. A recent survey by the federal government showed that more than 40% of the nation's nursing homes do not meet sanitary standards for food and more than one in four fail to administer drugs properly. The high turnover and lack of training of nursing aides contributes to the low quality of care. A recently enacted federal law requires training for nursing aides, but a lack of federal funds may delay or undermine the success of the program.

Home health care and respite care services are limited nationwide. Forty-two states fund limited home care services, including respite care and homemaker and personal care services, through a waiver program under Medicaid. However, all these programs combined serve only 100,000 elderly and disabled Americans, fully half of them in five states: Florida, California, Illinois, Oregon, and New York. Meanwhile, one million seriously disabled elderly living at home receive no assistance at all. Only 13 states require training for home health care aides. Around-the-clock home care can cost up to $70,000 a year, with each home visit costing between $50-$200.

Families across the country are competing just to get their children and elders on waiting lists for day care, despite its high cost. Only 1,400 adult day care centers exist nationwide, serving 66,000 persons. There are long waiting lists to get into these programs, which can cost up to $50 a day. A California survey revealed that 136,254 families were waiting for child care slots. In New York State an estimated 830,000 to 1,200,000 children needed child care; there are fewer than 135,000 licensed available slots. The cost of child care can be prohibitive for young families, averaging $3,000 a year for one child. Infant care can cost $100 a week. No federal standards exist for child or elder care centers, and state standards vary.

At a time when the need for elder care and child care services is increasing, there is a growing shortage of workers in both fields. The Department of Labor has projected a need for over 535,000 new long-term care workers by the year 2000. For nursing aides the turnover rate is 70-100% each year. For home care aides, the rate is 60%, with 80-90% leaving within two years. Sixty-seven percent of family day care workers and 42% of workers in child care centers leave their jobs each year.



Source: American Association of Retired Persons and the Travelers Foundation, A National Survey of Caregivers, November, 1988

The Federal Government Does Little To Assist Caregivers

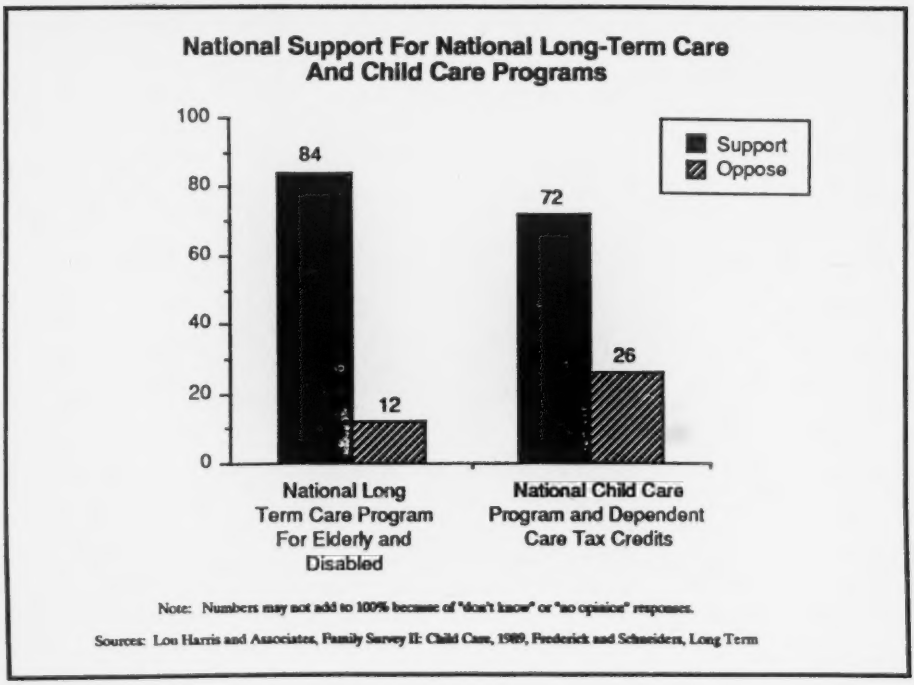
The United States and South Africa are the only industrialized countries without comprehensive health care or child care programs. Only a patchwork of federal and state programs exists to provide either elder care or child care assistance.

Less than five percent of total Medicare spending goes to cover long-term care services, including home health care and skilled nursing care. Designed to cover acute care costs, Medicare does not cover the costs associated with chronic illness, including nursing home care and home health care.

For families impoverished by health care costs, Medicaid will pay for institutionalization but provides very limited home care. A change in Medicaid eligibility under the new Catastrophic Coverage Act will allow a spouse caregiver to retain more income (122% of the federal poverty line) and resources (at least $12,000), while Medicaid would cover the cost to institutionalize her spouse. However, spousal impoverishment continues to exist for spouses who provide home care, as Medicaid covers very few of these costs. Therefore, a disabled spouse often must choose between premature institutionalization or draining his spouse's resources by remaining at home.

The Dependent Care Tax Credit has had a limited impact on caregivers. This credit can be used by employed families to subtract a portion of their child and elder care expenses from their federal taxes owed. Because the credit is not refundable, the many families that owe no taxes, and most lower-income families, are not reimbursed for their expenses. Additionally, very few families can use this credit for elder care expenses because of eligibility restrictions. The elder dependent must spend at least eight hours a day in the taxpayer's home and must be the taxpayer's financial dependent. With these restrictions, less than 10% of the $3.7 billion in tax credits are for the care of elderly dependents.

Despite the growing need, the federal government has cut back on money for elder and child care services. The federal government funds the Social Services Block Grant (Title XX of the Social Security Act) that is used by states to subsidize elder and child care services. Federal funding in 1989 of Title XX ($2.7 billion) is less than half what it was in 1977 (adjusting for inflation). Because of this federal reduction, 16 states have cut back on elder care services, while 26 have cut back on child care.



Note: Numbers may not add to 100% because of "don't know" or "no opinion" responses.

Sources: Lou Harris and Associates, Family Survey II: Child Care, 1989, Frederick and Schneiders, Long Term

Impact Of Caregiving On Caregivers

Given the lack of supportive services, family caregivers bear the brunt of the burden. Without the proper help, the rewards of caregiving are often overshadowed by the demands. Some of the demands are similar whether caregiving to adults or children. Caregiving can take time away from family, friends, and social activities, cause strife at work or an unplanned exit from the work force, and drain already-tight budgets.

Yet despite some similarities, important differences exist between caring for a healthy child and caring for a disabled person—either a child or adult. The costs of a chronic illness can impoverish families, while the emotional and physical impact can be devastating.

Women's Income In Comparison To Men's

	Men	Women	Women's As % Of Men's
Annual Median Income			
Total	$26,722	$17,504	66%
20-24	14,665	12,905	88%
25-34	23,804	17,583	74%
35-44	30,655	19,897	65%
45-54	32,821	19,087	58%
55-64	30,946	17,831	58%
65+	29,715	19,178	65%
Mean Monthly Pension Income 65+	$670	$370	55%
Percent Receiving	45.2%	21.5%	
Median Monthly Social Security Income	$521	$440	84%

Sources: Bureau of the Census, Money Income and Poverty in the United States: 1987, Tables 7-8; American Association of Retired Persons, Facts About Older Women, 1987; Bureau of the Census, March 1987 Current Population Survey, unpublished data; Social Security Administration, Social Security Bulletin, 1987.

Caregiving duties bear directly on women's lower wages, lower pension earnings, lower social security benefits, and higher health care costs. The direct costs to women who provide care are evident: $3,000 per child per year for child care; $70,000 per year for around-the-clock home care; $25,000 a year for nursing home care. With a longer life expectancy and no public health care coverage of chronic illness, many women can expect to spend their "golden years" drained of their income from a caregiving experience. The hidden financial costs to the caregiver of leaving the work force or accepting less demanding jobs are equally important and often overlooked.

Mainly due to caregiving responsibilities, women average 11.5 years out of the paid labor force, while men average 1.3 years. In a national survey, 11% of the caregivers to the elderly stated they left work because of caregiving responsibilities. Another study reported over a quarter (28%) of working caregivers were considering giving up their jobs.

Even when women do not leave the labor force, they often choose jobs with fewer demands and less pay because of caregiving duties. The average earnings of a working woman who gives birth drop $3,000 the first year and about $5,000-6,000 annually the next two years. The wage gap between women and men is greatest between age 45 to 64, when full-time male workers are at the height of their earning power and women are earning basically what they did in younger years.

Family caregivers to the elderly are disproportionately poor. Nearly one in three caregivers to the elderly are poor and 57% have lower or middle incomes. Caregiving wives and other caregiving women are more likely than caregiving men to be poor or near-poor. Both male and female caregivers to the elderly are more likely to have incomes below poverty compared to the population at large.

The physical and emotional demands of long-term caregiving can create health problems. Caregivers often postpone attending to their own medical needs while the care recipient is in their care. Many caregivers, particularly midlife and older women, suffer from the physical distress known as "caregiver's syndrome," developed from years of physical strain in the care of parents and then spouses. Lifting and turning a disabled adult can result in bursitis, can damage the spine and lower back, and can quicken the advance of osteoporosis. Repetitive, heavy lifting can increase even younger caregivers' chances of developing arthritis.

Researchers have found that caring for a loved one whose condition is deteriorating can lead to depression, anxiety, frustration, helplessness, sleeplessness, lowered morale, and emotional exhaustion. Caregivers of elders with Alzheimer's disease, particularly older women who live with and take care of their husbands, report high levels of stress and low levels of life satisfaction.

Conflicts Between Work and Family

The working world was not designed with the family in mind. In the past, women cared for children and elders at home. As more and more women seek employment out of economic necessity, women are experiencing serious conflicts between job and family responsibilities. Over half the caregivers of elders and infants and more than seven out of ten women (71%) with children under 18 are employed full-time.

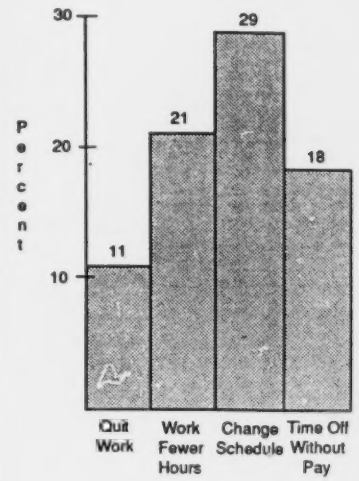
Men's caregiving responsibilities, though still not as great as women's, have an impact upon their work performance. Times have changed—but most employers have not. If employers continue to ignore the needs of their workers, most of whom are caregivers, work productivity will suffer. If rather than adapting business practices to workers' real world responsibilities, employers consciously or unconsciously are placing workers with families on a slower "mommy track," theso employers will discover that mothers are not the only employees with work and family conflicts. Indeed, only orphans with no children could be placed on the fast track to professional success.

Job performance can suffer from caregiving responsibilities. A survey of managers found many reporting excessive telephone use by caregiving employees (64%), absenteeism (67%), lateness (73%), and unscheduled time off from work (75%). Almost half the corporate respondents noted decreased productivity and work quality. Almost three in five women, and one in three men say that child care concerns interfere with work. More than one in five (22%) employees caring for elders report they have not had a vacation from caregiving responsibilities for a year or more.

Few employers offer flexible work schedules to assist caregivers. Compulsory overtime and rotating shifts are common in many occupations, making scheduling of caregiving difficult. Only about 12% of full-time workers can vary the time they begin or end work. Seven in ten working mothers want part-time employment, flexible hours, or work they can do in their homes. Fully one-third of employed caregivers to the elderly report they have lost time from work or have come in late as a result of caregiving duties.

Few employers provide supportive services for caregivers. Only 200 of the nation's six million employers offer any assistance with elder care, with 100 of these simply providing long-term care insurance. Stride Rite Corp. will be opening the first corporate-sponsored intergenerational care center, providing both elder and child care. Presently, only about 4,000 employers provide any child care services, with the vast majority providing information and referral services only. Several large employers, including IBM and Hallmark Cards, offer referral services toemployees for day care for children, elders, and disabled family members. Remington Products pioneered a respite care program, paying half the cost of care for a limited period of time. Travelers Corp. sponsors lunchtime information seminars and weekly support groups for caregivers of elders.

Working Caregivers To The Elderly Adjust Work Schedules To Give Care



Source: 1982 Long-Term Care Survey/Informal Caregivers Survey

Seven states have enacted Family and Medical Leave legislation to provide job protection for caregivers who need a temporary leave. Some employers fire workers who need a temporary leave to handle a family crisis. Three states now provide job protection for a caregiver on temporary leave after the birth, adoption, or serious health condition of a child: Oregon, Rhode Island, and Minnesota. Four states also recognize that caregiving includes the care of a seriously ill spouse or parent: Maine and Wisconsin for the private and public sector, and Maryland and Connecticut for state employees only.

Women Who Care

"In looking back, I can't help but compare the birth of a newborn and the care it requires with the care of a terminal patient. They are both very dependent on their mother/caregiver. Observe the networking that goes on when a newborn makes an entrance into our world. I was always surrounded with help and information when my babies were born.... On the other hand, the subjects of the bedridden cancer patient and the probable death are subjects that are avoided, even ignored. There is a definite need for information in dealing with death, no matter what the loved one's age. Death and dying are taboo subjects. No one wanted to talk to Mother and me, though we needed to talk about it."

— Dorothy, a caregiver to both her mother, who was recovering from eye surgery, and her father, who was dying of cancer.

"Age 75, in good health, describes me-but many of our friends and acquaintances have not had this good luck. Examples are all around us of the need to improve day care and respite care for adults and children. Money—as well as lives—could be saved by relieving the unbearable burdens many—most often women—carry through both youth and old age. Improve home care-and avoid institutional (expensive!) care as long as possible."

— OWL member, Connecticut Mother's Day 1989

"The problem of caregiving faced our family. For 10 years my sister gave up her own personal life to care for our elderly parents. She was unable to get adequate help so was frequently faced with caring for them 24 hours a day. Luckily, being a teacher, I had long vacations so I traveled to their home to help out during all of these vacations. Finally, it became too much of a responsibility. Reluctantly they had to be in a nursing home for the last two years of their lives."

— OWL member, Washington State Mother's Day 1989

"There should be some kind of 'bill of rights' for caregivers spelling out that you can only give what you give. And that should be acceptable. You shouldn't be criticized if you can't do more. And this bill of rights should include things you have to do for yourself. You have to be a caregiver for yourself, also. Unfortunately, in marriage, a woman ends up being a caregiver meeting her husband's needs. But there is nobody meeting her needs."

— Jill, a caregiver to her husband who suffered from Parkinson's disease.

"Among the people who called [the Philadelphia Geriatric Center] for help in one typical day were: an exhausted, 70-year-old woman who could no longer go on caring for her disabled, 93-year-old mother; a recently widowed 50-year-old who had just completed her education in preparation for a return to work, but found that her mother had Alzheimer's disease and could not be left alone; a couple in their late 60s with three frail parents between them; a divorcee of 57 who was caring for two disabled sons, a 6-year-old grandchild, and an 87-year-old wheelchair bound mother; and a young couple in their early 30s, about to have a first child, who had taken two older people into their home—the wife's terminally ill mother and the confused, incontinent grandmother for whom the mother had been caring."

— Elaine Brody, Philadelphia Geriatric Center

"Then we were suddenly faced with my father's incontinence. He was terribly embarrassed, but I told him, 'you cleaned me up once and now it's my turn.' We laughed together as he said, 'I always refused to do that job.' Then he lost his ability to shave and wash himself. This meant 'big kid' diapers (as my children called them) and my growing even more muscles to lift him in and out of the bathtub. With time, my father became more and more quiet, often staring into his lap for long hours. He missed my mother. He forgot he was holding his cigarette and would burn his fingers or his clothes. From then on, I couldn't leave him alone. I remember with humor the day he looked at me and said, 'Marg, I wish I could get on a motorcycle and hit the road!' I realized then how much he suffered by being so restrained."

— Margaret

Sources: Tish Sommers and Laurie Shields, Women Take Care: The Consequences of Caregiving in Today's Society, 1987; Elaine M. Brody, "Parent Care as a Normative Family Stress," The Gerontologist, vol. 25, no. 1, 1985.

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SECTION IV

The Dependent Elder, and Workplace Support For the Family Caregiver Some Public Policy Considerations

Michael A. Creedon, D.S.W.*

The central support system for the elderly in our society is the family. Many studies have confirmed the preeminent role of family care. The GAO in a 1977 study of Cleveland stated that 80% of the community care was provided by family members. A 1984 study by Nielsen and Robinson estimated the value of in-home services to dementia victims provided by family and friends at somewhere between 26.7 and 30.53 billion dollars. Since federal and state outlays for Medicare and Medicaid now exceed $150 billion per year, and families care for a much broader range of elderly problems than Alzheimers, we can assert that informal care provided by family and significant others now provides many billions of dollars in care value. The 1.4 million elderly currently in nursing homes are mirrored by a similar number confined to bed at home. Without family care the number of nursing home residents would certainly swell rapidly and the cost to federal and state treasuries would also grow at an unacceptable rate. Our society must prepare for the doubling of our 85+ population over the next ten years. This will also stimulate demand for long term care.

Working Caregivers

The growing population of at-risk elderly and the rapid rise in health care costs intensify the public policy interest in family care. However, family care is in jeopardy today due to the rising proportion of caregivers who work outside the home.

A recent AARP survey (March 1989) has found that 55% of caregivers for the elderly in America also hold down a job outside the home, and the average age of all caregivers in the survey was 47. A study conducted by a group of researchers at the University of Bridgeport found the most frequent age group of working caregivers was 40-45. In studies conducted by Brody (1985) and Friss and Enright (1987), some 11-12% of working caregivers had quit work to provide care. These were predominantly lower level employees who could not afford to purchase care.

Flexible Work and Leave

The research on working caregivers for the elderly has found that time is the single most important need of caregivers. Only 15% of American companies offer flexible work schedules, yet we know from the experience of companies such as IBM that productivity does not decrease with such schedules. Leave of absence policies are also important. Leaves for child care have been available for quite some time. Over the last two or three years, many companies have changed child care leave policies to "Dependent Care Leave," thus allowing caregivers for dependent adults or elders to make use of such leave. We need to stress that care of elders is much less predictable - both in onset and course - than child care. Consequently, caregivers need flexible leave (an example might be up to six months or a year leave within a six year period), along with flexibility in their work schedules.

Informational Assistance

Information is a central need for most caregivers, especially in the initial phase of care. Some employers now provide written informational resources (The Pepsico Eldercare Guide is an example), others offer telephone 800 number professional information services. However, many also need counseling assistance. Ideally such aid should be provided by an Employee Assistance Program. EAP's are widespread in the business community but are presently primarily expert in alcohol and drug abuse problems. There is an urgent need to stimulate the development of eldercare expertise among EAP personnel. The Travelers Companies experience suggests that EAP staff may expect that currently some 5% of their calls for assistance will relate to eldercare, but this can be discovered only after careful screening of presenting problems such as "exhaustion" and "stress."

Other Supports

Other forms of assistance to working caregivers could include adult day care access (Stride Rite), respite care cost matching (Remington), home assessment service (currently being planned by several companies). We need to recognize that we are at an early stage of the development of working caregiver support services. Over time we will discover the most effective and efficient ways to enable workers to continue as workers and caregivers. A recent dissertation study by Viola Pirie at Columbia University (1989) suggests that the greatest difficulty faced by working caregivers is the mood of their dependent

elderly relative. In such a case an educational seminar, or a counseling session about dealing with the depressed, could be the most effective contribution made by the workplace support program.

A Model Legislative Response

A bill is currently being developed by Conway Collis, member of the California State Board of Equalization, to offer tax credits to companies that develop eldercare support programs. The bill, currently in draft stage, is appended as an example of a stimulative tax credit approach to this issue. A tax credit program to stimulate corporate support of child care was enacted in 1989. The eldercare tax credit was conceived as companion legislation. While this particular draft legislation may not be the ideal approach for either state or for congressional response, it offers a starting point for legislative action.

A tax credit to employers for eldercare support programs should be considered a highly efficient way to stimulate non-public service to caregivers. In view of the rapid rise in Medicaid costs to the states, any support for the caregiving family through employer tax credits is also likely to be more than offset by reduced pressure on Medicaid budgets. The working caregiver is in most states the unsung and unreimbursed alternative to formal services, which are publicly funded in whole or in part.

Dependent Care Assistance Plans

Direct support of eldercare services by pre-tax salary set aside should also be available to working caregivers. Dependent

Care Assistance Plans are presently very adaptive to the support of child care, though they do not allow sufficiently for shift work or other situations which reduce the attractiveness or availability of child day care. However, a provision which requires that the dependent be living with the working caregiver eight hours a day is obviously disruptive of eldercare arrangements for many families. Likewise, requirements that the caregiver be responsible for 51% of the cost of care, and that the elder be dependent for tax purposes, are very burdensome and restrictive. Appropriate adaptation of the Internal Revenue Code is obviously necessary if this important option is to be available to caregivers for the elderly. Such adaptation might include a waiver of the living-in requirement for eldercare and a reduction of the cost of care provision from 51% to perhaps 30% for eldercare.

It is important to note that caregiving workers are presently providing cash support for their older relatives. In a 1989 survey, AARP found that the nationwide average cash support was some $117 per month. A Los Angeles area study by Andrew Scharlach of The University of Southern California reported contributions of over $200 per month on an average, and 67% of employee caregivers in a study of several Connecticut corporations reported providing financial support to older relatives (Creedon and Wagner, 1987). Availability of Dependent Care Assistance Plans (DCAPs) would stimulate additional cash support for older relatives. The track record of DCAPs in the child care area suggests that they are very efficiently used by

caregivers. Because eldercare is quite likely to become a charge on the Federal or State budget if no family care is available, tax revenue losses attributable to DCAP use are likely to be offset on the long term care expenditure side under Medicaid and other programs. DCAP use would require an average of at least two dollars of private expenditure on care for every dollar in tax loss incurred, and would offer a powerful incentive for expanded family support of services for the elderly. DCAP availability for adult day care, in conjunction with the growing trend toward medicaid reimbursement for adult day care, would provide a powerful stimulus to the growth of this lower cost alternative to nursing home care. In an era of rapid growth in the 85+ population and reduced availability of full-time care by working family members, we very much need to foster such options as day care and respite care. It therefore seems urgent that the tax writing committees both on the Federal and State levels consider the expansion of DCAP availability for eldercare.

Tax incentives could also greatly stimulate both the development of long term care insurance packages that offer options for coverage of parents, and the uptake of such options by employees. Obviously, insurance coverage that reduces the likelihood of Medicaid dependency among nursing home residents would alleviate that revenue drain on both the state and federal levels. Neither tax credits for corporate expenditures related to eldercare programs for employees nor adaptation of the IRS code regarding DCAPs, nor tax incentives for long term care insurance, represent an exhaustive list of public policy

approaches to the phenomenon of the working caregiver for the elderly. However, these measures would contribute substantially to the development of appropriate supports for caregivers in the 1990's.

* Dr. Creedon is Director of Corporate Programs at the National Council on the Aging.

PRELIMINARY DRAFT
FOR DISCUSSION ONLY

EMPLOYER CONTRIBUTIONS FOR ELDER CARE SERVICES; OR COSTS TO ADMINISTER VARIOUS EMPLOYER PROGRAMS; OR ESTABLISH OR EXPAND AN ADULT DAY OR ADULT DAY HEALTH CARE PROGRAM OR FACILITY

Section 17053.33 (a) (1) For taxable years beginning on or after January 1, 1990, and before January 1, 1997, there shall be allowed as a credit against the "net tax" (as defined by Section 17039) an amount equal to 30 percent of the amounts determined under subdivision (b).

(2) The credit amount allowed to an employer under this section shall not exceed $50,000 for any taxable year.

(3) For taxable years beginning in 1990, expenses incurred before the date this bill is chaptered shall not be included in the amount determined under subdivision (b).

(b) The amount of expenditures eligible for the credit allowed by this section shall be the sum of --

(1) The cost paid or incurred by the employer for contributions to elder care services, which includes but are not limited to:

(A) In-house, locally-produced or nationwide referral programs that offer information to the employer's California employees concerning the different resources available in various communities for elder care services.

(B) Educational seminars concerning elder care issues, which are made available to the employer's California employees.

(C) Elder care support groups that can provide support for the employer's California employees.

(D) Employee pamphlets providing elder care information to the employer's California employees.

(E) A California in-house social case worker or other counseling professional with a degree or certificate in gerontology, who is available to counsel and work with the employer's California employees.

(2) The amounts paid or incurred by the employer to administer indirect programs, such as flextime, liberal personal leave policies, job sharing, employee assistance programs, or dependent care spending accounts, for the employer's California employees who have a need to provide adult day or adult day health care for any of the qualified individuals described in Section 17053.35 so that the employee is able to be gainfully employed by the employer.

(3) (A) The amounts paid or incurred by the employer for start up expenses, as defined in subparagraph (B), of establishing an adult day or adult day health care program or facility, or expanding an existing adult day or adult day health care program or facility. The program or facility shall be located in California on or nearsite and used to provide care for any of the qualified individuals described in Section 17053.35 so that the California employee is able to be gainfully employed by the employer.

PRELIMINARY DRAFT
FOR DISCUSSION ONLY

(B) For purposes of this section, start up expenses means:

(i) Site preparation, construction, renovation, architectural plans or acquisition of facilities for the purpose of establishing or expending on or nearsite facilities.

(ii) Feasibility studies, whether or not a facility is built or the program is expanded.

(iii) Other related costs.

(c) (4) The amounts described in subdivision (b) shall be eligible for the credit allowed by this section only when paid or incurred primarily to benefit the employer's California employee.

(d) For purposes of paragraph (1) of subdivision (b), "elder care" means medical or nonmedical care for a person 55 years of age or older, and also includes persons under 55 who are chronically ill or impaired if the person would benefit from adult day or adult day health care.

(e) With the exception of a husband or wife, if two or more employers share in the amounts eligible for the credit provided by this section, each employer shall be eligible to receive a tax credit with respect to his, her or its respective share of the amounts paid or incurred. In the case of a husband or wife who files a separate return, the credit may be taken by either or equally divided between them.

(f)(1) In the case where the credit allowed under this section exceeds the "net tax," the excess may be carried over to reduce the "net tax" in the following year, and succeeding years if necessary, until the credit has been exhausted.

(2) If the credit carryovers from preceding taxable years allowed under paragraph (1) plus the credit allowed for the taxable year under subdivision (a) would exceed an aggregate total of fifty thousand dollars ($50,000), then the credit allowed to reduce the "net tax" under this section for the taxable year shall be limited to fifty thousand dollars ($50,000) and the amount in excess of the fifty thousand dollars ($50,000) limit may be carried over and applied against the "net tax" in the following year, and succeeding years if necessary, in accordance with this paragraph.

(g) No deduction shall be allowed as otherwise provided in this part for that portion of expenses paid or incurred for the taxable year which is equal to the amount of the credit allowed under this section attributable to those expenses.

(h) In lieu of claiming the tax credit provided by this section, the employer may elect to take depreciation pursuant to Section 17250. In addition, the employer may take depreciation pursuant to that section for the cost of a facility in excess of the amount of the tax credit claimed under this section.

(i) The basis for any facility owned by the employer for which a credit is allowed under this section shall be reduced by the amount of the credit attributable to the

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facility. The basis adjustment shall be made for the taxable year for which the credit is allowed.

(j)(1) In order to be eligible for the credit the employer shall submit to the Franchise Tax Board, upon request, a statement certifying the following:

(A) That the amounts for which the credit is being claimed are paid or incurred primarily for the benefit of his, her or its employee;

(B) Declaring for which paragraph under subdivision (b) that the credit is being claimed;

(C) In the case where the credit is claimed with respect to establishing a program or facility under paragraph (3) of subdivision (b) that the facility will be licensed and in operation for at least 36 consecutive months after completion; and

(D) In the case where the credit is claimed with respect to an existing program or facility under paragraph (3) of subdivision (b), that it is operating under a required license and will continue to operate for 36 consecutive months after the expansion.

(2) If the facility or program for which a credit is claimed pursuant to paragraph (3) of subdivision (b) fails to operate, is disposed of or ceases to operate within 36 months after completion, that portion of the credit claimed which represents the remaining portion of the 36-month period shall be added to the employer's tax liability in the taxable year of that inoperation, disposition or nonuse.

(k) This section shall remain in effect only until December 1, 1997 and as of that date is repealed, unless a later enacted statute, which is enacted before December 1, 1997, deletes or extends the date. However, any unused credit may continue to be carried forward, as provided in subdivision (f), until the credit has been exhausted.

Personal Income Tax Law

EMPLOYER CONTRIBUTIONS TO ADULT DAY OR ADULT DAY HEALTH CARE FACILITIES AND CERTAIN SERVICES

Section 17053.34 (a) (1) For taxable years beginning on or after January 1, 1990 and before January 1, 1997, there shall be allowed as a credit against the "net tax" (as defined by Section 17039) an amount equal to 50 percent of the amounts paid or incurred by the employer for contributions to an adult day care facility, health day care facility, qualified home health care services or in-home care services, including supportive care, for the purpose provided in subdivision (c). The facilities and services shall be be located or performed in California.

(2) For taxable years beginning in 1990, expenses incurred before the date this bill is chaptered shall not be included in the amount determined under subdivision (a).

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(b) The amount of the credit allowed for any taxable years shall not exceed $600 for each employee.

(c) (1) The contribution shall be made for the care of the individuals described in Section 17053.35 so that the employer's California employee is able to be gainfully employed by the employer.

(2) "Qualified home health care service" means those services approved by a physician, which include, but are not limited to, nursing care, speech therapy, physical therapy, occupational therapy, respiratory therapy and a home health aide.

(3) "Contributions" include employer reimbursements to employees for the employee's care plan expenses, or direct payment to care programs or providers, or both.

(4) The term "employee" includes, for any year, an individual who is an employee within the meaning of Section 401(c)(1) of the Internal Revenue Code (relating to self-employed individuals).

(d) With the exception of a husband or wife, if two or more employer share in the amounts eligible for the credit provided by this section, each employer shall be eligible to receive a tax credit with respect to his, her or its respective share of the amounts paid or incurred. In the case of a husband or wife who files a separate return, the credit may be taken by either or equally divided between them.

(e) In the case where an employer makes contributions and also collects fees from the employee to support a facility owned and operated by the employer, no credit shall be allowed under this section for contributions in the amount, if any, by which the sum of the contributions and fees exceed the total cost of providing care. The Franchise Tax Board may require information about fees collected from the employee.

(f) In the case where the credit allowed by this section exceeds the "net tax," the excess may be carried over to reduce the "net tax" in the following year, and succeeding years if necessary, until the credit has been exhausted.

(g) The credit shall not be available to an employer if the care provided as a benefit to the employee is provided by an individual who:

(1) Qualifies as the employer's or that employee's dependent or is the employer's or that employee's spouse under paragraph (1) of subdivision (d) of Section 17054.

(2) Is (within the meaning of Section 17056) the employer's or that employee's son, stepson, daughter, or stepdaughter who is under the age of 19 at the close of that taxable year.

(h) The contributions to a qualified care plan shall not discriminate in favor of employees who are officers, owners, or highly compensated, or their dependents.

(i) No deduction shall be allowed or otherwise provided in this part for that portion of expenses paid or incurred for the taxable year which is equal to the amount of the

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credit allowed under this section attributable to those expenses.

(j) In lieu of claiming the tax credit provided by this section, the employer may elect to take depreciation pursuant to Section 17250. In addition, the employer may take depreciation pursuant to that section for the cost of a facility in excess of the amount of the tax credit claimed under this section.

(k) The basis for any facility owned by the employer for which a credit is allowed under this section shall be reduced by the amount of the credit attributable to the facility. The basis adjustment shall be made for the taxable year for which the credit is allowed.

(l) This section shall remain in effect only until December 1, 1997, and as of that date is repealed, unless a later enacted statute, which is enacted before December 1, 1997, deletes or extends the date. However, any unused credit may continue to be carried forward, as provided in subdivision (f), until the credit has been exhausted.

Section 17053.35. For purposes of Section 17053.33 and Section 17053.34 --

(a) The following are qualified individuals:

(1) The employee's spouse; or

(2) The employee's son, daughter, descendent of either, stepson, stepdaughter, descendent of either, brother, sister, stepbrother, stepsister, mother, father, or ancestor of either, stepparent, niece, nephew, aunt, uncle, son-in-law, daughter-in-law, father-in-law, mother-in-law, brother-in-law, or sister-in-law; or

(3) Any other individual who is a member of the employee's principal place of residence during the time in which the individual is to receive adult day care, adult day health care, qualified home health care services or in-home care services, including supportive care.

(b) "Adult day care" means an organized day program which provides nonmedical care to persons 18 years of age or older in need of personal services, supervision, or assistance essential for sustaining the activities of daily living or for protection of the individual on less than a 24-hour basis. "Adult day care facility" means a center, place or building which provides adult day care under a license as required by law. For purposes of this section an adult day care facility includes a "social day care facility" which is a community-based group program designed to meet the needs of functionally impaired adults through an individual plan of care in a structured comprehensive program that provides a variety of social and related support services in a protective setting on less than a 24-hour basis.

(c) "Adult day health care" means an organized day program of therapeutic, social, and health activities and services provided pursuant to Chapter 3.3 of Division 2 of the Health

and Safety Code to elderly persons with functional impairments, either physical or mental, for the purpose of restoring or maintaining optimal capacity for self-care. Provided on a short-term basis, adult day health care serves as a transition from a health facility or home health program to personal independence. Provided on a long-term basis, it serves as an option to institutionalization in long-term care facilities, when 24-hour skilled nursing care is not medically necessary or viewed as desirable by the individual or his or her family. "Adult day health care facility" means a center, place or building which provides adult day health care under a license as required by law.

Bank and Corporation Tax Law — Proposed Legislation

EMPLOYER CONTRIBUTIONS FOR ELDER CARE SERVICES; OR COSTS TO ADMINISTER CERTAIN EMPLOYER PROGRAMS; OR ESTABLISH OR EXPAND AN ADULT DAY OR ADULT DAY HEALTH CARE PROGRAM OR FACILITY

Section 23636. (a) (1) For income years beginning on or after January 1, 1990, and before January 1, 1997, there shall be allowed as a credit against the " tax" (as defined by Section 23036) an amount equal to 30 percent of the amounts determined under subdivision (b).

(2) The credit amount allowed to an employer under this section shall not exceed $50,000 for any taxable year.

(3) For income years beginning in 1990, expenses incurred before the date this bill is chaptered shall not be included in the amount determined under subdivision (b).

(b) The amount of expenditures eligible for the credit allowed by this section shall be the sum of --

(1) The cost paid or incurred by the employer for contributions to elder care services, which includes but are not limited to:

(A) In-house, locally-produced or nationwide referral programs that offer information to the employer's California employees concerning the different resources available in various communities for elder care services.

(B) Educational seminars concerning elder care issues, which are made available to the employer's California employees.

(C) Elder care support groups that can provide support for the employer's California employees.

(D) Employee pamphlets providing elder care information to the employer's California employees.

(E) A California in-house social case worker or other counseling professional with a degree or certificate in gerontology, who is available to counsel and work with the employer's California employees.

(2) The amounts paid or incurred by the employer to administer indirect programs, such as flextime, liberal personal leave policies, job sharing, employee assistance programs, or dependent care spending accounts, for the employer's California employees who have a need to provide

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adult day or adult day health care for any of the qualified individuals described in Section 23638 so that the employee is able to be gainfully employed by the employer.

(3) (A) The amounts paid or incurred by the employer for start up expenses, as defined in subparagraph (B), of establishing an adult day or adult day health care program or facility, or expanding an existing adult day or adult day health care program or facility. The program or facility shall be located in California on or nearsite and used to provide care for any of the qualified individuals described in Section 23638 so that the California employee is able to be gainfully employed by the employer.

(B) For purposes of this section, start up expenses means:

(i) Site preparation, construction, renovation, architectural plans or acquisition of facilities for the purpose of establishing or expending on or nearsite facilities.

(ii) Feasibility studies, whether or not a facility is built or the program is expanded.

(iii) Other related costs.

(c) (4) The amounts described in subdivision (b) shall be eligible for the credit allowed by this section only when paid or incurred primarily to benefit the employer's California employee.

(d) For purposes of paragraph (1) of subdivision (b), "elder care" means medical or nonmedical care for a person 55 years of age or older, and also includes persons under 55 who are chronically ill or impaired if the person would benefit from adult day care or adult day health care.

(e) If two or more employers share in the amounts eligible for the credit provided by this section, each employer shall be eligible to receive a tax credit with respect to his, her or its respective share of the amounts paid or incurred.

(f)(1) In the case where the credit allowed under this section exceeds the "tax," the excess may be carried over to reduce the "tax" in the following year, and succeeding years if necessary, until the credit has been exhausted.

(2) If the credit carryovers from preceding income years allowed under paragraph (1) plus the credit allowed for the income year under subdivision (a) would exceed an aggregate total of fifty thousand dollars ($50,000), then the credit allowed to reduce the "tax" under this section for the income year shall be limited to fifty thousand dollars ($50,000) and the amount in excess of the fifty thousand dollars ($50,000) limit may be carried over and applied against the "tax" in the following year, and succeeding years if necessary, in accordance with this paragraph.

(g) No deduction shall be allowed as otherwise provided in this part for that portion of expenses paid or incurred for the income year which is equal to the amount of the credit allowed under this section attributable to those expenses.

(h) In lieu of claiming the tax credit provided by this section, the employer may elect to take depreciation

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pursuant to Section 24371.5. In addition, the employer may take depreciation pursuant to that section for the cost of a facility in excess of the amount of the tax credit claimed under this section.

(i) The basis for any facility owned by the employer for which a credit is allowed under this section shall be reduced by the amount of the credit attributable to the facility. The basis adjustment shall be made for the income year for which the credit is allowed.

(j)(1) In order to be eligible for the credit the employer shall submit to the Franchise Tax Board, upon request, a statement certifying the following:

(A) That the amounts for which the credit is being claimed are paid or incurred primarily to benefit its employee;

(B) Declaring for which paragraph under subdivision (b) that the credit is being claimed;

(C) In the case where the credit is claimed with respect to establishing a program or facility under paragraph (3) of subdivision (b) that the facility will be licensed and in operation for at least 36 consecutive months after completion; and

(D) In the case where the credit is claimed with respect to an existing program or facility under paragraph (3) of subdivision (b), that it is operating under a required license and will continue to operate for 36 consecutive months after the expansion.

(2) If the facility or program for which a credit is claimed pursuant to this section fails to operate, is disposed of or ceases to operate within 36 months after completion, that portion of the credit claimed which represents the remaining portion of the 36-month period shall be added to the employer's tax liability in the income year of that inoperation, disposition or nonuse.

(k) This section shall remain in effect only until December 1, 1997 and as of that date is repealed, unless a later enacted statute, which is enacted before December 1, 1997, deletes or extends the date. However, any unused credit may continue to be carried forward, as provided in subdivision (f), until the credit has been exhausted.

Bank and Corporation Tax Law

EMPLOYER CONTRIBUTIONS TO ADULT DAY OR ADULT DAY HEALTH CARE FACILITIES AND CERTAIN SERVICES

Section 23637. (a) (1) For income years beginning on or after January 1, 1990 and before January 1, 1997, there shall be allowed as a credit against the "tax" (as defined by Section 23036) an amount equal to 50 percent of the amounts paid or incurred by the employer for contributions to an adult day care facility, health day care facility, qualified home health care services or in-home care services, including supportive care, for the purpose

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provided in subdivision (c). The facilities and services shall be be located or performed in California.

(2) For income years beginning in 1990, expenses incurred before the date this bill is chaptered shall not be included in the amount determined under subdivision (a).

(b) The amount of the credit allowed for any income years shall not exceed $600 for each employee.

(c) (1) The contribution shall be made for the care of the individuals described in Section 23638 so that the employer's California employee is able to be gainfully employed by the employer.

(2) "Qualified home health care service" means those services approved by a physician, which include, but are not limited to, nursing care, speech therapy, physical therapy, occupational therapy, respiratory therapy and a home health aide.

(3) "Contributions" include employer reimbursements to employees for the employee's care plan expenses, or direct payment to care programs or providers, or both.

(4) The term "employee" includes, for any year, an individual who is an employee within the meaning of Section 401(c)(1) of the Internal Revenue Code (relating to self-employed individuals).

(d) If two or more employer share in the amounts eligible for the credit provided by this section, each employer shall be eligible to receive a tax credit with respect to his, her or its respective share of the amounts paid or incurred.

(e) In the case where an employer makes contributions and also collects fees from the employee to support a facility owned and operated by the employer, no credit shall be allowed under this section for contributions in the amount, if any, by which the sum of the contributions and fees exceed the total cost of providing care. The Franchise Tax Board may require information about fees collected from the employee.

(f) In the case where the credit allowed by this section exceeds the "tax," the excess may be carried over to reduce the "tax" in the following year, and succeeding years if necessary, until the credit has been exhausted.

(g) The credit shall not be available to an employer if the care provided as a benefit to the employee is provided by an individual who:

(1) Qualifies as the dependent under paragraph (1) of subdivision (d) of Section 17054 of the bank's or corporation's officer or owner or that employee.

(2) Is (within the meaning of Section 17056) the son, stepson, daughter, or stepdaughter, under the age of 19 at the close of that taxable year, of the bank's or corporation's officer or owner or that employee.

(h) The contributions to a qualified care plan shall not discriminate in favor of employees who are officers, owners, or highly compensated, or their dependents.

(i) No deduction shall be allowed or otherwise provided in this part for that portion of expenses paid or incurred

for the income year which is equal to the amount of the credit allowed under this section attributable to those expenses.

(j) In lieu of claiming the tax credit provided by this section, the employer may elect to take depreciation pursuant to Section 24371.5. In addition, the employer may take depreciation pursuant to that section for the cost of a facility in excess of the amount of the tax credit claimed under this section.

(k) The basis for any facility owned by the employer for which a credit is allowed under this section shall be reduced by the amount of the credit attributable to the facility. The basis adjustment shall be made for the income year for which the credit is allowed.

(l) This section shall remain in effect only until December 1, 1997, and as of that date is repealed, unless a later enacted statute, which is enacted before December 1, 1997, deletes or extends the date. However, any unused credit may continue to be carried forward, as provided in subdivision (f), until the credit has been exhausted.

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Section 23638. For purposes of Section 23636 and Section 23637 --

(a) The following are qualified individuals:

(1) The employee's spouse; or

(2) The employee's son, daughter, descendent of either, stepson, stepdaughter, descendent of either, brother, sister, stepbrother, stepsister, mother, father, or ancestor of either, stepparent, niece, nephew, aunt, uncle, son-in-law, daughter-in-law, father-in-law, mother-in-law, brother-in-law, or sister-in-law; or

(3) Any other individual who is a member of the employee's principal place of residence during the time in which the individual is to receive adult day care, adult day health care, qualified home health care services or in-home care services, including supportive care.

(b) "Adult day care" means an organized day program which provides nonmedical care to persons 18 years of age or older in need of personal services, supervision, or assistance essential for sustaining the activities of daily living or for protection of the individual on less than a 24-hour basis. "Adult day care facility" means a center, place or building which provides adult day care under a license as required by law. For purposes of this section an adult day care facility includes a "social day care facility" which is a community-based group program designed to meet the needs of functionally impaired adults through an individual plan of care in a structured comprehensive program that provides a variety of social and related support services in a protective setting on less than a 24-hour basis.

(c) "Adult day health care" means an organized day program of therapeutic, social, and health activities and service

provided pursuant to Chapter 3.3 of Division 2 of the Health and Safety Code to elderly persons with functional impairments, either physical or mental, for the purpose of restoring or maintaining optimal capacity for self-care. Provided on a short-term basis, adult day health care serves as a transition from a health facility or home health program to personal independence. Provided on a long-term basis, it serves as an option to institutionalization in long-term care facilities, when 24-hour skilled nursing care is not medically necessary or viewed as desirable by the individual or his or her family. "Adult day health care facility" means a center, place or building which provides adult day health care under a license as required by law.

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EXCERPTS FROM

"ELDERCARE: AN ISSUES OVERVIEW"

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SUBMITTED TO

SUBCOMMITTEE ON HUMAN SERVICES

OF THE

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SELECT COMMITTEE ON AGING

Services Available in the Community

The Federal Older Americans Act (OAA), passed in 1965 as part of the Great Society, set forth a philosophy for program planning that gave first priority to supporting elders' ability to remain in the community and thereby avoid higher cost institutional care. To this end, the OAA supports several types of services: "congregate and home-delivered meals, senior centers . . . nursing home ombudsman activities, and community service employment programs."[1] To carry out this mission, in 1973, Congress established Area Agencies on Aging (AAAs) to serve as local vehicles for addressing issues and concerns involving older persons. As originally conceived by Congress, the system of Area Agencies and State Units on Aging (SUAs) was meant to encompass both services funded under the OAA and services supported by other federal, state, and local programs. In 1978 and 1981, new areas of service gained priority on the OAA agenda, including transportation, outreach, information and referral, and in-home (homemaker, home health aide, personal care, chore, escort, shopping, and telephone reassurance services) and legal services.

Under the Reagan administration, cuts in federal spending for many social programs adversely affected OAA services. The fiscal year 1988 budget request attempted to include all programs under the Office of Human Development Services, including OAA, in a single blanket appropriation. Because Congress believed that this amalgamation of "26 separate discretionary activities" would have "significantly reduced funding" for OAA programs, it rejected the proposal and moved to passed six additional authorizations under Title III of the OAA.[2] Title III funds are made available as grants to the SUAs; in turn, the SUAs award these funds to 670 AAAs for the purposes of planning, coordinating, and advocating for a comprehensive network of services to the aged.

In addition to Title III, programs for elders are also funded under Title XVIII (Medicare), Title XIX (Medicaid) and Title XX (Social Services) of the Social Security Act. However, it is currently difficult to assess which funds spent under Title XX actually flow into services for elders and their caregivers because of modifications made under the Omnibus Budget Reconciliation Act.

Area Agencies on Aging

Because of their legislative mandate to conduct comprehensive needs assessment and program planning, the AAAs serve a leadership role in coordinating the activities of providers of services to elders. The agencies' relationship to caregivers, however, is less clear. When caregivers are themselves elderly, they are also the appropriate target of AAA efforts. However, the AAAs' concentration on older adults may impede programs that should serve younger caregivers. Unless the agencies can expand their defined clientele to include all caregivers regardless of age, strategies that coordinate efforts with other departments will have to be devised. As an example, to overcome the eligibility requirements of the social services block grant to serve only those 60 years of age or older, the Wisconsin Office on Aging mounted a Respite Care Demonstration project that was conducted through local mental health agencies.

In Spokane, Washington, the AAA developed a working relationship with the community mental health center to offer an in-home case-management program for elderly persons and their families. Fourteen other agencies funded by the Eastern Washington AAA negotiated agreements with the mental health center that detailed how client referral, joint training, and resource sharing would be handled.[3]

Limited funding and legislative mandate may make it difficult for AAAs to offer communitywide services to caregivers. Nonetheless, these agencies are a valuable resource for those seeking to plan programs that serve the needs of those providing eldercare. Their goals, which are derived from the mission of the OAA, make them natural allies for community and business groups attempting to create or expand services targeted to this population.

As indicated in earlier chapters, the costs to society in lost productivity, compromised health, or family disruption among overtaxed caregivers are significant. This evidence provides a convincing rationale for providing service and changing policy to supply relief to employed caregivers. Designing services that support families that care for the dependent elderly, however, requires meeting several challenges.

SALIENT ISSUES IN THE DESIGN OF SERVICES

First, program planners must overcome obstacles to utilizing services that are inherent in the caregiving situation. Second, they must plan services that respect the racial and cultural diversity found among families providing care to elders. Third, they must attempt to coordinate the scarce resources that are devoted to family support efforts. Finally, they must address certain dilemmas that arise in choosing target groups, staffing patterns, and strategies to publicize the programs they hope to develop.

Barriers to Service Utilization

Services that will ease the burdens of caregivers are best designed with several key features of the caregiving situation in mind. First, most families value inde-

pendence, self-sufficiency, and privacy. For spouses, in particular, caregiving is simply an extension of activities they have engaged in throughout their married lives. Consequently, they do not identify themselves as "caregivers," even when they experience significant strain. Children and siblings may also believe that "families should take care of their own." Moreover, some families see services that have income eligibility requirements as "welfare" or a "handout" and may therefore refuse to apply for such assistance. These attitudes and values will lead families to contact service providers only at times of crisis. Yet, their ability to effectively utilize services is often diminished by the overwhelming demands they face in their current situations. Requesting information, participating in a support group, or even arranging for respite care may require more energy than they can muster.

Second, caregiving situations are not static. Resources that were previously unavailable may materialize; competing demands on caregivers' time may abate; or the requirements of care may subside as an elder accommodates to disability. On the other hand, the caregiver's health may decline or the demands for care may escalate, causing a breakdown in previous coping patterns. It is essential that service providers recognize the dynamic nature of caregiving arrangements and design programs that allow continued participation by caregivers who must come and go according to the exigencies of their particular situations.

Finally, it is important to see caregiving as a continuum of potential supports—ranging from simple services (such as phone calls to an elderly parent who is living independently) to complicated ones (such as providing the equivalent of skilled nursing care to a disabled spouse.) The burdens that caregivers experience are equally diverse and multifaceted. Consequently, services that meet the needs of adult children separated by some distance from their frail parents may be inappropriate for others who reside with and care for an elderly relative. Likewise, some caregivers receive support from other family members, or friends and neighbors, while others do not have such assistance; different kinds of support will be required for each.

Because caregiving covers such diverse activities and is dynamic, program planners should aim to provide a flexible and responsive set of services. Of course, resources are limited and priorities must be assigned to meeting different types of need; nonetheless, strategies can be adopted to increase the likelihood that comprehensive and coordinated programs will be offered.

Respecting Racial and Ethnic Diversity

Because of pervasive social, physical, and economic deprivation, many elderly in minority groups endure lower income, poorer housing, and shorter life expectancies than the population at large. In fact, the greatest proportion of the elderly population who are most in need are minorities.[4] A language barrier denies many minority groups access to the formal system of care. It is equally the case that service strategies that conflict with culturally defined value systems and beliefs seriously compromise acceptance of available support services for minority families.

If the service system in a society and the recipients of that service do not share the same values, conflicts in communication and goals are the likely outcome. Basic

discrepancies surrounding essential issues such as methods of expressing human need and customary patterns of kinship support have contributed to a mismatch between the problems of minority families and available solutions within the existing service delivery system. Community organizations can bridge the gap between the dominant value system and minority cultural perspectives when providers working closely with minority families demonstrate an understanding of cultural differences. An awareness of and sensitivity to salient aspects of the cultural heritage of these groups is essential to the development of effective family support programs.

Coordination of Scarce Resources

Because resources for program development may be limited, it will be more feasible to provide a range of programs when organizations—social agencies, community groups, and businesses—in a particular area coordinate their efforts. Such collaboration will vary from one locale to another, dictated by each community's mores, industrial structure, and existing social services. Older communities may have a rich array of social service agencies that operate under different auspices, each with methods for providing programs. Newer communities that have had less time to build a network of social services may rely on business initiative or government direction and funding to initiate services for family caregivers. Likewise, in some areas, the county is the preferred unit for organizing services, while in others the responsibility devolves to localities.

In general, resources to meet the needs of families that are caring for impaired elders in the community are more likely to be concentrated in urban areas. Promoting cooperation among service agencies, whether public or private, is essential in rural regions where resources are spread over wide geographic distances. Service organizations should focus efforts on developing strategies that will maximize the contributions of voluntary religious and civic organizations to the support of families that are caring for dependent elders.

Even in urban areas, it may be difficult to coordinate resources or introduce new services because social service agencies, although more numerous, have been traditionally tied to particular constituencies or programs. The potential to sustain chronically impaired elders in the community when ability to care for themselves diminishes has been undermined by the dichotomy found in many urban settings between the provision of health and social services. Families seeking home care support must negotiate a complex bureaucratic system in which agencies are separated according to disease specialty and service category. These circumstances have created barriers to meaningful problem solving and frustrated caregivers' efforts to meet real need when the solutions to problems transcend arbitrarily assigned divisions of authority.

STRATEGIES FOR SUPPORTING CAREGIVERS

There are many ways to support those caring for frail elderly relatives. As discussed in Chapter 3, employed caregivers have identified various employee bene-

fits and personnel policies that would help them meet elders' need for care. In addition, businesses can provide a critical leadership function as advocates for their employees with federal, state, and local governments and with community organizations. Businesses can initiate private-public partnerships to develop programs that will serve not only their own employees but also the community at large.

Numerous studies have identified four basic kinds of service programs that caregivers need:

1. Education about the changes that occur with age, and training in caregiving skills;
2. Information about services available to those providing or requiring care;
3. Emotional support; and
4. A break from caregiving.

The appropriate mix of services will vary from one area to another, and decisions about which programs should be offered will be based on the kinds of caregiving arrangements found in a particular community. Program development will also be affected by the nature of resources that can be committed to specific programs. Some programs require little in the way of planning time, staffing, or funding; others may be difficult or costly to initiate. Thus, decisions about program development will be guided both by caregiver need and agency resources.

First Steps—Recognizing Caregivers' Efforts and Providing Needed Information

Even when funding is minimal, providing basic information will assist a broad spectrum of caregivers. Hence, this is a good way to begin addressing caregiver concerns. Family members are often overwhelmed by the demands that caregiving places on them. Even when a number of programs and services exist, caregivers may not have the time or energy to ferret out the information about location, cost, or eligibility requirements. Having a list of resources may, in and of itself, help to alleviate a sense of isolation and hopelessness. To reach a broad range of caregivers, such a list must be distributed in strategic locations—doctors' offices, company newsletters, supermarkets, libraries, and P.T.A. meetings, for example.

To be effective, formal information and referral programs need to identify or build a network of service providers in the community. Network building activities extend from taking an inventory of agencies and groups that offer services to dependent elders and their caregivers to convening a work group of area service providers to conduct a needs assessment or develop programs. A directory of resources can be developed by a business coalition or social service provider in the area, but other groups are also well suited to the task. The local hospital's auxiliary, church groups, or even a scout troop may wish to undertake such a project.

Information and referral efforts are not restricted to localities. In 1983, Wisconsin's State Office on Aging published "Help At A Glance: A Handbook of Caregiver Support Resources," which provides an overview of the situations caregivers face and a listing of adult day care, respite care, self-help systems, supplementary serv-

ices, and some less familiar services that are available in various locations throughout the state.

Information can also be provided to caregivers through workshops or meetings that focus on caregivers and the process of aging. Such meetings spotlight the problems caregivers encounter and the services required to address them. They may appeal not only to current caregivers, but also to members of the community who are interested in the problems of the aging. Such individuals can prove to be a valuable resource in program development. Moreover, community workshops may also educate providers about one another's programs or about the scope of family caregivers' needs. Consequently, they can facilitate future efforts to coordinate services.

Because meetings are effective tools for outreach and constituency building, they should be held at times and in settings that invite the broadest possible participation. For example, workshops may draw a different audience if offered through community groups (e.g., the public library or adult education programs) than if they are based in a social service agency. Several organizations (see Appendix A for a listing) have put together "packages" for groups wishing to run a workshop program in their community. These packages provide both planning information and suggestions for about what to cover.

Information or referrals to agencies that can appropriately evaluate an elder's needs can help caregivers develop a plan for care. However, continued monitoring and reassessment of care needs are both necessary and time-consuming. Some agencies provide case-management or monitoring services; in some areas, networks of private social service professionals offer these services. Recently, several companies have contracted for such services to be made available to their employees. Whether caregivers choose to coordinate care on their own or use case-management services, they will need information about the way to select and judge the quality of personnel and the services provided.

Services That Enhance the Coping Capacity of Caregivers

Providing care to an elderly family member often requires that the caregiver expand his or her repertoire of skills in problem management as he or she juggles multiple roles and their attendant tasks. A sense of frustration and fatigue often results from this daily confrontation with demands that never seem to cease. In addition to the physical strain of assisting an elder with activities of daily living, the caregiver faces the emotional struggle of coping with changes in a once-familiar person. Other family members also feel distress, thus previous patterns of coping may begin to unravel.

Support Groups

A variety of approaches may help to relieve caregivers' stress. Individual or family counseling is offered by many family service agencies and mental health centers. Frequently, mutual support groups also provide an effective vehicle for meeting caregivers' needs for emotional support, skills training, and education. The *Idea*

Book on Caregiver Support Groups succinctly states the benefits caregivers derive from participating in such groups:

> First, the caregiver's feelings of loneliness and isolation are reduced in the nonjudgmental company of others facing similar situations. Second, the caregiver receives information about the aging process and about available community resources. With increased knowledge, the caregiver's ability to understand and communicate with the dependent older relative, with other family members and with health and human service professionals improves. Third, interaction among caregivers with similar problems and concerns helps develop skills in stress management, problem solving and home care techniques. Sharing coping strategies gives caregivers an opportunity to contribute to the solutions of others' problems, and thus to help themselves by helping others. Finally, group participation builds a support network that may well carry beyond group meetings into enduring mutual help and friendship.[5]

As awareness of caregivers' needs has grown, many communities and businesses have responded by establishing support groups. In some instances, community awareness workshops or education programs stimulate the establishment of support groups by bringing together individuals who share common concerns. Many groups are organized by caregivers themselves. For example, "The Children of Aging Parents" grew out of conversations between friends who were facing problems caring for ill parents. Other groups are initiated by social service agencies, human resource departments within firms, or community organizations. Still others are established by caregivers collaborating with agency staff.

When members themselves organize and lead a support group, it is usually referred to as a self-help group. Because the premise of such groups is that each member has something to contribute to the others, it is important that leadership tasks are shared by as many members as possible. Even so, the primary responsibility for organizing meetings usually falls on one or two members. Because the demands involved in caring for an elderly relative may consume much of the caregiver's time and energy, many groups rely on joint leadership with a professional facilitator. A professional can help to get the group started, ensure that the tasks required for each meeting are completed, and serve as a link between group members and community services.

Leaders—whether caregivers or professionals—should be able to separate personal needs from the needs of the group and its members, and possess knowledge of group behavior, communication skills, and a commitment "to work toward group goals."[6] Other desirable attributes will be determined by the nature of the group.

There are many varieties of support groups. Some groups are planned as short-termed endeavors; others are ongoing. Some are funded through an agency or community organization; others rely on membership dues. Some limit membership to those who join within a particular period of time; others have open membership. Further, research on group process has found that when group participants face similar situations, the group is more cohesive. Hence, it may be desirable to have some groups specifically for spouses—for example, "Wives Who Care"—and others for adult children caregivers—for instance, "DEBUT: Daughters Bridging the Unknown

Together." Those caring for elders with particular impairments—Alzheimer's and Related Disorders Support Groups, for example—may wish to meet together. Each of these dimensions will influence the content of group meetings.

Whatever the focus of a support group, most meetings provide information to caregivers and opportunities for them to discuss their experiences and receive support. Speakers from health and social service agencies, community organizations, or educational institutions can be invited to talk about topics of interest to members. Training in techniques for handling particular problems is also an element of many group meetings.

Several excellent books provide an overview of support group development and many organizations have published manuals for those wishing to establish such programs. These guides are listed in Appendix A.

Services that Provide Respite for Family Members

There are many ways to provide time out for weary caregivers. In some families, other relatives—siblings, children, nieces and nephews, and sometimes grandchilden—pitch in to give the primary caregiver a needed break. Some families can also rely on neighbors for occasional assistance. However, many families do not have such help available on a regular basis. For them, formal services that provide respite will allow them to continue an arduous undertaking.

Many services—even though not identified as "respite care"—can provide relief for overburdened caregivers. Meals-on-wheels, homemaker and chore services, personal care attendants, as well as adult day care and home health programs give caregivers for frail elders some time to pursue their own interests.

In contrast, formal respite care programs are primarily designed to allow caregivers time off. Respite care programs range from all-day care in an institutional setting staffed by professionals, to occasional visits by a volunteer "companion" in the older person's home. Some programs offer service on weekends or even for a few weeks while family members take a vacation. Others care for the elderly relative overnight. Programs are housed in senior centers, adult day care centers, social service agencies, and sometimes in nursing homes. They may be sponsored by community organizations and churches, by health or social services or agencies, or by caregivers themselves.

Depending on the setting for the program and its sponsorship, staffing patterns will vary. Some programs use trained unpaid volunteers; others use stipend volunteers; still others have paid staff. Even when the respite workers are volunteers, however, most programs have a paid program coordinator to handle referrals, assessment, and assignment. A few programs are respite care cooperatives in which family members exchange services to provide relief for one another.

One innovative program is "Elder Care Share" (ECS) sponsored by the South-central Michigan Commission on Aging in Kalamazoo with funding from the Health Care Financing Administration. Families that join ECS train one another to care for their parents and other relatives, taking turns providing respite care for varying time periods. The cooperative elects officers who conduct the business of the group—

handling respite requests, arranging workshops, and recording debit and credit hours for all members. The group produced a handbook listing the terms of membership in the cooperative and a manual covering the program's background, policies, and guidelines. Because it relies on volunteers—the family members themselves—this program has the potential to provide respite care at low cost. However, it requires tremendous outlays of time and energy by caregivers, and hence may not be appropriate when such a commitment of resources is not possible.

A more easily implemented, though more expensive, approach provides respite companions to families caring for elderly relatives. A core of staff members oversees training of companions, conducts case-finding or handles referrals, communicates program goals and accomplishments to the community, and generates funding for service continuation.

In sum, supporting caregivers' efforts requires developing a network of services. After caregivers receive information and education, a logical next step in comprehensive program planning is to address the differing needs of caregivers. Based on an assessment of these needs and an evaluation of their relative weights, services such as case management/monitoring, adult day care, support groups, or respite companion programs may be developed. The responsibility for developing such programs rests with business organizations, social service providers, and various levels of government. How this issue is currently being addressed is the subject of the next two chapters.

Notes

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Long Distance Eldercare: Spanning the Miles with a New Benefit

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INTRODUCTION

Adult children taking care of their elderly parents is not a new phenomenon, but work and family conflicts and other stresses of modern life, coupled with a growing elderly population, will force society to confront serious eldercare policy questions throughout the 1990s, experts told BNA.

Concern about how the stress of eldercare responsibilities on employees affects corporate profits will lead many companies to make eldercare their most prominent employee benefit of the next decade, these experts say. Some employers, such as The Philip Morris Companies, already are reporting that eldercare services are being requested more often by employees than child care.

By the year 2000, eldercare programs "will be as commonplace as employee assistance programs are today," Tyler Phillips, president of The Partnership Group, which operates the ElderCare Connection, a national eldercare information and referral service, told BNA.

By the year 2000, elder care programs "will be as commonplace as employee assistance programs are today. . ."

The Graying of America

Fueling the eldercare concern is the graying of the U.S. population. Each day in the United States, more than 5,000 people reach their 65t' birthday, according to the American Association of Retired rsons (AARP).

Moreover, the percentage of very elderly people among those over 65—people who are 75 and older and most likely to need eldercare—also is expected to increase from 40 percent in 1980 to 50 percent by the year 2000, the National Council on Aging (NCOA) says.

Although many of these people will need daily care, family members are finding it increasingly difficult to provide that care, experts say. This is due partly to the fact that women, who comprise the majority of eldercare providers, are entering the workforce in increasingly larger numbers, and an increasing number of workers, both men and women, are being promoted to jobs that are far from where their parents live, Michael Creedon, director of corporate programs at NCOA, told BNA.

Nevertheless, family members and friends continue to provide 80 percent of the eldercare in the United States, according to the

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University of Bridgeport in Connecticut. Fifty-five percent of the people who take care of elderly relatives work outside the home, according to AARP.

Long distances often add to the problems facing many eldercare providers. Long-distance care providers often are under great stress, and they frequently manage the care of their elderly relatives as a series of crises, Andrew Scharlach, assistant professor of social work and gerontology at the University of Southern California, told BNA.

Many employees engaged in long-distance or short-distance eldercare often are absent or late for work, use the telephone excessively, or quit their jobs, a BNA survey found.

Baby Boomers Face Eldercare Responsibilities

The long-distance eldercare problem will get worse as baby boom children pursuing white collar careers scramble to advance amid intense competition, accepting job promotions and transfers that put them hundreds or even thousands of miles away from their elderly relatives, Creedon told BNA. An increasing number of blue collar workers may be required to provide short-distance eldercare because they seldom will be transferred, he added.

This special report examines the problems facing long-distance providers and workers who provide care in their homes or nearby, and what employers are doing to help them. The report also tells how employers can reduce the stress caused by providing long-distance care.

The report also chronicles the experiences of five companies that have eldercare programs or are about to launch them. These include:

- The Travelers Companies, which will start a nationwide eldercare information and referral service in January 1990. The service is the latest of several eldercare benefits offered by Travelers, one of the first employers to survey its employees on their eldercare needs.
- Aetna Life & Casualty employees' overwhelming response to eldercare programs. The company, which began offering eldercare benefits on a hunch that they were needed, has completed a statistical profile of its employees who are eldercare providers.

Many employees engaged in long-distance or short-distance eldercare often are absent or late for work, use the telephone excessively, or quit their jobs, a BNA survey found.

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- U.S. Sprint, which began a nationwide eldercare information and referral service in August to prevent eldercare problems.
- The Philip Morris Companies, The American Express Co., J.P. Morgan Co., Inc., and New York City's joint effort to help provide eldercare, perhaps the only public/private eldercare partnership in the country.
- IBM officials' belief that their company reflects trends in society, a belief that led the firm to become the first to launch a nationwide eldercare information and referral service.

This special report is the 22nd in a series produced by the BNA PLUS Research and Special Projects Unit of the Bureau of National Affairs, Inc. Drew Douglas, managing editor, coordinated work on the report. Steven Teske, staff editor, researched and wrote this report. Senior copy editor Roger Feinthel was copy editor, and staff editor Gwen Moulton was production editor.

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ELDERCARE: EMPLOYEE BENEFIT OF THE 1990s

When Charles Shaw's 74-year old mother feli down stairs and broke her hip in December 1988, Shaw canceled his business appointments, got on the next flight from his home near Hartford, Conn., and began an 1,200-mile trip by plane and auto to his parents' home in Canton, Ill.

Shaw arrived at 1 a.m. the next day, following a four-hour car ride from Chicago's O'Hare International Airport, tired but anxious to help his mother and father, and himself, get through the crisis.

Shaw's mother already was recuperating in the hospital, so he and his brother set out to find a nursing home for their 80-year-old father, who earlier had suffered a stroke and was unable to care for himself. After making about a half-dozen telephone calls, they placed their father in a facility and arranged for their mother to live there after she was discharged from the hospital.

Satisfied with the arrangements they had made, Shaw and his brother left Canton a few days later and returned to their jobs. Shaw, 51, is corporate director of benefits for The Travelers Companies in Hartford; his brother works in Dallas.

Worrying About Care

Although Shaw felt his father was receiving adequate care, he began worrying about his mother, who discharged herself from the nursing home against his wishes and moved back home a few months after he returned to Hartford.

Rather than make numerous telephone calls to find out how he could help her with day-to-day activities, Shaw contacted the Travelers' employee assistance program. The program gave him a list of care options, from which Shaw arranged for a visiting nurse to check on his mother and for a meals-on-wheels program to bring her lunch daily.

"When you're so far away, there are times without question you feel helpless," Shaw told BNA. "But I feel considerably better knowing someone is checking in on her."

"When you're so far away, there are times without question you feel helpless. . ."

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Travelers' EAP program "lets me sleep real easy at night while my mother is 1,200 miles away," Shaw added.

Throughout the United States, a small but growing number of companies are trying to help employees who must provide care for parents or other elderly relatives who live far away (long-distance eldercare), or for those who live with them or close by.

States are responding to eldercare needs by enacting family leave laws or are using area agencies on aging to establish long-distance eldercare information and referral services.

Travelers, for example, will expand its eldercare benefits in January 1990 when it launches a national information and referral service, allowing employees to obtain eldercare information about relatives anywhere in the country with one telephone call.

Many experts say eldercare will be the fastest growing corporate benefit of the 1990s, as the working population ages and corporate officers such as Shaw experience the frustrations involved with such care.

Employer Investment

"It's not really a benefit, it's an investment for employers," Perry D. Cohen, president of Unison Corp., a Bethesda, Md., consulting firm that advises business on eldercare, told BNA.

About 35 companies have implemented eldercare benefits, according to a 1988 study by the Employee Benefits Research Institute, and a study of 100 companies by the University of Bridgeport in Connecticut found that 15 percent were considering offering them.

In addition, Congress is considering the Family and Medical Leave Act of 1989 (S 345, HR 770), which would require employers to provide employees unpaid leave for the care of an ill parent or child or after the birth of a child.

States are responding to eldercare needs by enacting family leave laws or are using area agencies on aging to establish long-distance eldercare information and referral services. Illinois, for example, has launched such a service, called "ElderLink."

In addition, unions are negotiating for such services. The recent contract agreement between the Communication Workers of America and the American Telephone and Telegraph Co., for example, requires the company to start a national information and referral service for eldercare by January 1991.

"It's a hot button," Phillips, of The Partnership Group Inc., told BNA.

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Meridy Rachor, director of eldercare services for The Partnership Group, and others predict eldercare could become even more popular than child care as a corporate benefit. "Not everybody has children they're concerned about, but everybody has parents," Rachor told BNA.

Eldercare as an employee benefit is growing much more rapidly than child care because the need for child care alerted many employers to the value of work and family programs, Andrew Scharlach, assistant professor of social work and gerontology at the University of Southern California, told BNA.

Also spurring interest is a growing awareness of the "graying of America" and the fact that eldercare issues are more likely than child care problems to affect top corporate officials, most of whom are older white males, Scharlach said.

Employers that are starting eldercare programs also are acting out of self-interest, experts told BNA. NCOA and the National Association of State Units on Aging (NASUA) estimate that employee eldercare problems are costing U.S. business $8 billion a year in lost work days.

The groups based the figure on a study conducted for GTE California that estimated the annual cost of days lost for eldercare at $2 million for a 25,000-member workforce in 1987.

Saving Health Benefits

Employers also can save health benefits costs by implementing eldercare services, because eldercare providers appear to use health benefits to cope with the stress that results from being responsible for care, NCOA and NASUA say in the report, "Eldercare in the Workplace."

"If the workplace offers no support for the caregiver through employee assistance programs or other benefits, the employee may not seek help until physical effects occur," the report says.

"Thus, the health benefit may be the major source of corporate support available to most caregivers. Needless to say, this is a very expensive employee support program for such a service."

A February 1989 BNA survey found that 44 percent of officials from 225 firms were aware of employees in their organization who care for elderly parents and relatives. Fifty-two percent of those said

"If the workplace offers no support for the caregiver through employee assistance programs or other benefits, the employee may not seek help until physical effects occur. . ."

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their employers experienced problems as a result of their eldercare responsibilities. Sixty-six percent of the firms responding offered some type of assistance to employees with eldercare responsibilities.

Absenteeism appears to be the most common problem among employees who are taking care of elderly relatives, the survey found. Thirty-seven percent of companies whose respondents knew of employees who were providing eldercare have experienced high rates of absence among those employees. Tardiness was a problem for 22 percent of the firms, while stress was a problem at 20 percent, BNA found.

Demographic trends indicate that both the number of older Americans and the average age of the workers who in many cases will care for them is increasing. About 30 million Americans are over age 65, and the figure is expected to rise to 50 million by the early 21st century, according to NCOA and NASUA. About 12 million people now provide care to 6.6 million adults, according to NCOA.

The average age of U.S. workers will rise to 39 by the year 2000, according to the U.S. Department of Labor. Eldercare issues become prominent for many workers in the their late 30s and early 40s, experts told BNA. A recent study by the University of Bridgeport found that the average age of eldercare providers was 46.

The most significant labor-related factor affecting eldercare is the growing number of women in the workforce . . . because women provide the majority of care.

The most significant labor-related factor affecting eldercare is the growing number of women in the workforce, NCOA and NASUA say, because women provide the majority of care. The University of Bridgeport found that up to 67 percent of care providers are women.

More Men Involved

Terry Freeman, manager of home office employee assistance programs for Travelers, said men are involved more often in long-distance eldercare than in short-distance care because many men pursue careers that require them to relocate frequently.

Most surveys have found that about 25 percent of all people in the workforce are providing eldercare. IBM says 30 percent of its workforce is providing eldercare.

In the BNA survey, 83 percent of corporate officials estimated that no more than 10 percent of those in their workforces are providing care for elderly relatives. This figure indicates that corporations

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need to be educated about the extent of the eldercare problem, according to NCOA and NASUA.

No studies have been conducted to determine the number of employees engaged in long-distance eldercare, but initial data from the few companies operating information and referral services indicate long-distance care providers comprise the majority of those who seek help.

Seventy-five percent of calls to U.S. Sprint's eldercare information and referral service, 52 percent of those to IBM's, and 40 percent of those to a similar service at Aetna Life and Casualty have involved long-distance care.

Some corporations, including IBM, define long-distance care as care given to an elderly family member at least 100 miles away. Creedon of NCOA defines such care as care that requires employees to be away from their job for one day or longer.

Long-distance eldercare providers give a wide variety of help to their elderly family members, including arranging in-home nursing care, enrolling them in meals-on-wheels programs, and helping with finances.

Although few employer eldercare programs have been started with the specific needs of long-distance care providers in mind, many provide services sought by long-distance caregivers.

This includes information on understanding the aging process and on care options for elderly relatives. Long-distance care providers also often seek counseling to ease the guilt and other feelings that frequently accompany their care-giving duties, Creedon told BNA.

Employer responses to the eldercare problem include the adoption of flexible schedules and leaves and policies allowing the use of sick days to care for elderly relatives. Employers also sponsor care provider fairs, establish libraries with books and videotapes on the subject, and contract with outside firms for nationwide information and referral services.

Although few employer eldercare programs have been started with the specific needs of long-distance care providers in mind, many provide services sought by long-distance caregivers.

Information and Referral

Nationwide information and referral services are extremely helpful for employees who must provide long-distance eldercare because they often allow them to obtain information without leaving their

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homes or offices, experts told BNA. A few companies have contracted for such a service, including IBM, Travelers, and Aetna.

Some companies also are turning to private information and referral networks that employ case managers to handle employees' long-distance care needs.

One such firm, Aging Network Services in Bethesda, Md., has a network of 250 social workers around the country that contact care receivers to determine their needs and to monitor them while they are receiving care. The service also provides counseling to employees about the problems they face as eldercare providers.

Although most employers will not reveal what these services cost, Travelers says it spends between $1.5 million and $2.5 million a year for its national child care and eldercare information and referral service.

Aging Network Services charges up to $12 an employee per year for its most expensive package of services, according to Barbara Kane, co-founder of the firm.

Employers say the money they spend on eldercare services is more than offset by improved employee morale, recruitment, and retention.

"There's not the slightest doubt in my mind" that the money is well spent, Shaw told BNA. "Having gone through [a long-distance eldercare crisis] now, I realize more than ever the value of [eldercare programs] to our employees."

Employers say the money they spend on eldercare services is more than offset by improved employee morale, recruitment, and retention.

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PROBLEMS OF LONG DISTANCE CAREGIVERS

In long-distance eldercare, out-of-sight does not necessarily mean out-of-mind, experts on the issue told BNA.

People who must provide care for their parents or other elderly relatives living with them or in the same community often suffer from exhaustion and a lack of free time. Long-distance care providers—those who must provide care for elderly relatives who live far away—often must battle feelings of guilt and worry about the level of their involvement and frustration at not being able to obtain appropriate care, experts say.

People who must provide care for their parents or other elderly relatives living with them or in the same community often suffer from exhaustion and a lack of free time.

Among the problems facing long-distance eldercare providers are lack of knowledge about available resources; conflicts with siblings over how to arrange care, especially with those who live close to the person receiving care; and financial and work problems caused by frequent travel to where the care is being provided.

Psychological Stress Prominent

Experts say providing care for parents or elderly relatives nearby often is more physically exhausting than long-distance care, while long-distance care often causes more psychological stress.

"There's a lot of worry, just plain old worry" among long-distance care providers, Margaret Neal, a research associate at the Institute on Aging at Portland State University in Oregon, told BNA.

Long-distance care providers "have a continual concern about how they are doing," Donna L. Wagner, director of the Division of Human and Community Services at the University of Bridgeport in Connecticut, told BNA. "They worry about who's responsible for [their parents] on a daily basis and the quality of care they receive."

Worrying about whether they are doing the right thing for elderly family members often harms long-distance care providers' work and home lives, experts told BNA.

Among the questions long-distance providers frequently ask themselves are: Am I prepared for an emergency? Should I get my parents to come and live with me? Should they be put in a nursing home? How do I know my parents are telling me the truth about

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their situation? Am I doing the right thing in insisting on respite care for my parents?

These and other problems facing long-distance care providers often are the same as those asked by adult children caring for a parent or relative who lives with them or nearby, experts told BNA.

However, distance forces many long-distance eldercare providers to seek housing alternatives for their parents or relatives because they may be unfamiliar with their parents' living situation, Creedon told BNA.

In addition, long-distance care providers tend to rely more on formal care services than those responsible for short-distance care, although some first rely on a neighbor or friend of the elderly family member to take care of them.

Planning Ahead

Long-distance care providers also may plan more than those engaged in short-distance care, saving vacation and sick days, for example, to use in emergencies when an elderly family member is sick, Creedon said.

. . .distance forces many long-distance eldercare providers to seek housing alternatives for their parents or relatives because they may be unfamiliar with their parents' living situation. . .

Eldercare providers often act as case managers for the person for whom they are responsible, arranging for services such as transportation and home meal delivery, Lynn Osterkamp, research associate at the Gerontology Center at the University of Kansas in Lawrence, told BNA. Long-distance care providers find those duties much more difficult because they are so far away and no central eldercare information bank exists.

"If you're sitting in one part of the country, you've got to make a lot of phone calls," Osterkamp said.

Many employers' eldercare programs address the needs of long-distance and short-distance care providers, experts told BNA. Nevertheless, they said employers could offer specific services to help employees with long-distance eldercare responsibilities, such as travel subsidies or free long-distance calls to the people for whom they are providing care.

"It's a real advantage of companies to get involved [in an eldercare benefits program] to avoid crises" that often plague eldercare providers, Cohen of Unison Corp., told BNA.

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If they fail to avoid these crises, "a few years from now it's going to be a key manager gone for a couple of days" to solve an eldercare problem when the manager is most needed at work, Cohen added.

Many employers already are feeling the effects of unmanaged eldercare situations, according to experts. Because they live far away, long-distance care providers many times manage the care of a loved one as a series of crises requiring immediate attention.

In contrast, people involved in local eldercare can establish a routine of providing care, Scharlach of the University of Southern California, told BNA.

Long-distance care crises "totally turn everything upside down" in the lives of the providers, creating stress different from that experienced by those with a relative living in their home or nearby, who usually have more control of the situation, Scharlach said.

If a crisis occurs, "pretty tremendous expenditures of airfare and phone" can result, Neal added. "The financial side of [long-distance] caregiving is not inconsequential."

"The financial side of [long-distance] caregiving is not inconsequential."

Unaware of Services

Most people are not aware of services that are available until a crisis occurs, according to *Miles Away and Still Caring: A Guide for Long-Distance Caregivers*, published by the American Association of Retired Persons. For many others, the tension surrounding a crisis makes it difficult to take the necessary steps to intervene in the care receiver's life, according to people interviewed by BNA.

A crisis, such as a sudden illness of the care receiver, may recede and arise again later, Scharlach observed.

To prevent such crises, some companies are adopting eldercare programs to help both short-distance and long-distance care providers, Cohen said.

Many long-distance providers find care for their parents only to have their parents refuse to accept their help. This leaves the adult children feeling powerless to act and the feeling is exacerbated by the distance between the parents and their children, experts say.

"The hardest part of long-distance caregiving is getting your parents to accept help," Barbara Kane, co-founder of Aging Network Services in Bethesda, Md., told BNA. "It's very hard when you have a resistant parent who doesn't want change."

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Parents sometimes fire the visiting nurse or refuse to accept meals-on-wheels arranged by an adult child living in another part of the country, often without the child's knowledge, Kane said.

"The child will set up the service, return home, and the parents will just fire them, and the children will have to start all over again," Kane said.

Such action reflects the problems created by role reversals in which the adult children are caring for the parents. Some adult children treat their parents like children when they become ill or incapacitated, causing resentment in the parents, according to Wagner, a co-principal investigator in the University of Bridgeport's "Managing Eldercare in the Workplace Project."

Kane said some adult children move their parents closer to them even though the parents are capable of taking care of themselves, an action that separates the parents from their friends and puts them in an unfamiliar community.

As a result, "many parents feel like they are held hostage in their children's house," she told BNA.

Long-distance care providers are more likely to think a move is in the best interests of their parents because such providers are not where their parents live and therefore they are unable to evaluate their parents' situation, according to Neal.

Parents sometimes fire the visiting nurse or refuse to accept meals-on-wheels arranged by an adult child living in another part of the country, often without the child's knowledge. . .

In other cases, ill feelings between parents and adult children that have existed for decades interfere with eldercare decisions that must be made, Neal told BNA.

"There's nothing to indicate that things will be any different [between parents and adult children] than before even though we may be more mature," Neal said.

Insulating Children

Telephone calls, the basic link between long-distance eldercare providers and care receivers, also may add to care providers' sense of misgiving because parents who want to insulate their children from worry sometimes do not reveal their problems to them, Kane added.

Parents or elderly relatives "may rise to the occasion with every phone call," Kane said, hiding depression or illness. "They may cover up that they need help."

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Long-distance eldercare providers are more likely than their short-distance counterparts to find themselves in a crisis because it is difficult for them to determine their parents' health during a telephone conversation, Kane said. "It's hard to know if they are losing weight or suffering from a short-term memory loss," she commented.

Such factors can create stress different from, but not necessarily worse than, that experienced by eldercare providers with parents or relatives living in the same community or in their home, experts told BNA.

To help employees cope with such stress, employers should establish a wide variety of programs for local and long-distance care providers, experts say. Many, such as flexible leave arrangements, already have been adopted by employers to help parents take care of their children.

To help employees cope with such stress, employers should establish a wide variety of programs for local and long-distance care providers, experts say.

"New benefits are not the priority. They may not even be necessary," according to the NOCA and NASUA report. "Examining all existing practices that can contribute to work/family conflict is necessary. This includes looking at leave policies, workloads, schedules, even use of the telephone, as well as the traditional company-provided employee benefits."

However, employers should not use benefits designed to solve child care problems to help employees with eldercare responsibilities, experts told BNA.

NCOA and NASUA point out, for example, that day care is used more frequently by workers with small children than it is by employees with eldercare responsibilities; eldercare receivers may live long distances from those providing care; the care needs of elderly adults differ from those of children; elderly parents have more health problems than children; and parents have total responsibility for their children, whereas adult children usually are only partially responsible for their parents.

Eldercare More Complex

"Eldercare is so much more complex than child care," Kane said. She maintains that employees need much more counseling to help solve eldercare problems.

Programs designed to help long-distance care providers are available for employers, Creedon noted.

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Employers should establish toll-free 800 numbers that enable employees to call their parents or elderly relatives and they should provide financial support where possible to help them meet the costs associated with long-distance care, he said.

In addition, employers should contract for information and referral services to make sure employees are aware of their care options and the problems that face the elderly, Creedon said. Such a service also makes it easier to find help for elderly relatives living far away, experts say.

Employers also should adopt flexible leave policies and allow employees to use sick leave to care for ill relatives, Creedon said. Dependent care assistance plans also can be adopted for long-distance eldercare providers, and support groups can be established to give employees an opportunity to discuss their problems with counselors and co-workers, he added.

Care provider fairs held on company grounds also can be used to help educate workers about eldercare and to make them aware that they may soon face eldercare responsibilities, Creedon said. Employee assistance programs also can be used to provide assistance and counseling to long-distance care providers at little cost to employers, Creedon said.

Employees often need only the advice of a counselor to solve a long-distance eldercare crisis, Creedon offered.

"An awful lot of issues that face care providers are value questions that they need to talk out," he told BNA.

"Eldercare is so much more complex than child care . . ."

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THE COMMUNITY CARE CONNECTION

THE ESSENTIAL LINK IN CLIENT-CENTERED COMMUNITY-BASED LONG TERM CARE SYSTEMS
July 1989

"THE OVERALL OBJECTIVE OF THE TITLE III PROGRAM IS TO STRENGTHEN OR TO DEVELOP AT THE SUBSTATE OR AREA LEVEL A SYSTEM OF COORDINATED AND COMPREHENSIVE SERVICES FOR OLDER PERSONS - - SERVICES WHICH WILL ENABLE OLDER PERSONS TO LIVE IN THEIR HOMES OR OTHER PLACES OF RESIDENCE AS LONG AS POSSIBLE."

- from "Grants for State and Community Programs on Aging." Federal Register, vol. 38, no. 196, October 11, 1973.

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There is a pressing need for the development of a comprehensive long term care system in our nation. Regardless of the immediate fiscal constraints on the Federal budget, public consciousness about the issue has risen dramatically and the substantial growth in the numbers of persons of advanced age has given high visibility to an issue which cannot continue to be ignored.

The Area Agencies on Aging, fulfilling their mandate to develop local comprehensive, coordinated systems of home support services, have fifteen years' experience in addressing the very problems policy makers are currently wrestling with in attempting to devise a workable long term care program. Area Agencies on Aging have established care coordination units to prescribe and monitor services according to client need. These care coordination units enforce contracts for home health and support services to assure that standards for appropriate access, quality of care, and reasonable costs are met, and provide for the integration of those services on behalf of at-risk clients. Area Agencies on Aging in over half the states in the nation have solid care coordination systems and additional states are in the process of developing them.

These Area Agency on Aging coordinating units provide the local link that will allow the implementation of a Medicare or Medicaid comprehensive long term care program. The Area Agencies on Aging care coordination system is the oldest, most experienced, most extensive community-based long term care coordinating structure existing in the nation. With their solid individual care and community-wide coordination systems, Area Agencies on Aging are fully capable of meeting the principles upon which an effective long term care system must be based.

This paper is divided into three sections. One section reviews the conceptual difficulties in utilizing the existing Medicare and Medicaid systems in providing community-based long term care to older persons. The second section discusses the role of the Older Americans Act and Area Agencies on Aging in effectively providing community-based long term care. The final section presents several basic principles for long term care legislation.

Conceptual Problems for Existing Medicare and Medicaid Systems in Providing Community-Based Long Term Care

It is becoming apparent that in the near future Federal policy makers will establish a national long term care policy and program, very likely as part of the Medicare or Medicaid program.

In response to increased public interest and demand, Congressional leaders have introduced a flurry of bills, almost all emphasizing community-based long term home care, the overwhelming preference of disabled persons and their families. The bills reflect the fear of policy makers that, although the demand for home care is growing, the delivery of home care may not be satisfactorily managed and utilization and costs may spiral out of control. This fear is mirrored in the hesitancy of the private insurance industry to launch into long term care much beyond institutional care and the usual limited indemnity policies.

Public initiatives tend to build on federally-operated Medicare, an acute medical care system, or on Medicaid's state-operated extended care system, a primarily institutionally-based system. The massive reimbursement machinery in each of these systems makes available proven financial vehicles to facilitate the funding of a community-based long term care system. However, there are deep fundamental differences between long term home care and the care provided by the Medicare and Medicaid systems, and to extend their structures for service delivery to home care would leave unaddressed any effective measures to assure appropriate access to clients, reasonable cost to payers, and quality control of services.

Long Term Care Differs From Acute Care

Long term care is concerned not with cures of disease, but with consequences of disease and disability. While a long term care client may have drug regimen and therapy for an illness, long term care focuses on providing support for those who are seriously disabled and unable to perform such activities of daily living (ADLs) as getting in and out of a bed or chair, bathing, dressing, using the toilet, walking, or eating, and the instrumental activities of daily living (IADLs), such as preparing meals, grocery shopping, doing laundry, or performing housekeeping chores.

A medical episode encompasses a diagnosis of a disease or physical condition and a treatment designed to correct the problem and restore the patient to health. It lends itself to a generalized predictability of the expenditure of resources, such as that embodied in Medicare's prospective reimbursement system, and to the documentation of patient condition.

Long term care, on the other hand, deals not with diagnoses reflected in measurable and observable symptoms which can be readily charted for review, but with the infinite combinations of physical strength and abilities, mental stability, motility, tolerance for pain, cognition, sensory acuity, and emotional strength, as well as the safety and security of the care setting, and the family's willingness to help. These are factors which would confound the paper utilization review efforts used in acute care.

Long Term Home Care Differs From Long Term Institutional Care

The great majority of funds for all types of long term care is for room and board. Nursing homes, by providing shelter under one roof, consolidating meal preparation and laundry, and by standardizing the care regimen, can cut costs for twenty-four hour care. But if a client does not need the continuous intensive care of the nursing home and if the private resources of the client and public funds are used judiciously, home care can save public dollars. With home care, the client's own residence provides the shelter, the client may be helped or trained to perform activities of daily living, and family caregiving may provide help to complement the client's own resources. This type of caregiving is often lost in the institutional setting. Community agencies may provide formal services when the client and family caregivers are unable to perform them, often at much less expense than institutional care would require.

The standardization of nursing home care, which provides some cost cutting, tends to override the dissimilar conditions and disabilities of residents, promoting their passivity and dependence. The isolation of institutional care can provide the potential for abuse and neglect which have plagued the reputations of nursing homes for years. Home care, on the other hand, affords greater individual tailoring of care, and by involving the family and informal supports in the caregiving responsibilities, can increase the opportunity for monitoring of client needs.

But home care can also be abused. Home health care agencies are funded primarily through third party payer systems, as are nursing homes. However, home health care agencies are reimbursed on a fee-for-service basis rather than a per diem basis and can often times profit from a unilateral increase in the frequency and duration of services to a client. Further, unless care is monitored by a family and/or a case manager from an agency not vested in service delivery, neglect and/or abuse can occur. The types of surveys and evaluation systems currently used to monitor nursing homes would not be effective or appropriate for in-home care when living environments are enormously varied and widely dispersed.

The efficiency and effectiveness of home care can be assured through a system which can provide both client advocacy and the prudent expenditure of resources. It is in the national network of Area Agencies on Aging that such a system can be found.

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The Mission of the Older Americans Act in Community-Based Long Term Care

Area Agencies on Aging were created by the 1973 amendments to the Older Americans Act and charged with the responsibility to "strengthen or develop at the subetate or area level a system of comprehensive, and coordinated services for older persons — services which will enable older persons to live in their homes or other places of residence as long as possible." This was the first Federal venture into community-based long term care.

The Area Agencies on Aging, for the most part non-service-providing agencies, contract with local community agencies for the delivery of services to older persons. This contract process insures effectiveness and efficiency through competitive bidding and contract enforcement.

In the early 1980's, when health and human service systems were deregulated, service agencies proliferated and competition among them grew heated. It became apparent to Area Agencies that providers with conflicting purposes were becoming resistant to coordination, neither working together with clients nor sharing information about clients. The market system allowed providers to abandon their responsibility to unprofitable or difficult-to-serve elders, and appreciably raised the potential for abuse and neglect. Over time, the Area Agencies tightened their performance standards, targeted their services, and stepped up their monitoring, but it was obvious to Area Agencies on Aging that to fund the service system through performance-based contracts with select providers was not enough, that to serve the at-risk client required a coordination effort beginning with the individual client's needs and drawing in the appropriate services as those needs dictated. In response to the changes taking place in the service provider market system, Area Agencies moved into care coordination, (case/care management, as it is also called) not because it was mandated, but because it afforded them the opportunity to administer their funds and pool other resources in the best interests of vulnerable older persons, thus assuring appropriate access to quality services with maximum efficiency.

Care Coordination Assures Access To Appropriate Services

The Area Agency on Aging care coordinator can act as a gatekeeper, identifying at-risk clients who could avoid unnecessary institutional care by creating a home environment that the client can manage. The care coordinator, in consultation with the client and their family, designs a plan and manages the coordination of services from several agencies, and orchestrates the delivery of care. The care coordinator can also help with nursing home placement for those clients who require that level of care.

Care Coordination Assures Quality Care

The care coordinator should be a client-oriented monitor of the services prescribed in the care plans. With on-site visits, the care coordinator determines whether the tasks have been accomplished proficiently, what their impact has been, and whether there should be changes in care plans. On-site observations of the care plan implementation reveal first hand incidents of client neglect or abuse.

Care Coordination Contains Costs

The care coordinator, as a funder or an authorizer of services, can prevent the upscaling and over-utilization of services. As observers of the acute care industry are aware, when providers may at their discretion treat illness without regard to cost on a fee-for-service basis, patients tend to receive an amount and a level of care far beyond what is necessary for quality treatment. This can be an equally disturbing problem in community-based long term care. For example, a provider may try to justify home health care when less expensive homemaker service would be more appropriate, attend to the client four days a week when three.days would do as well, or continue the service weeks after it is no longer needed. The care coordinator, without a vested interest in

inflating services, but instead with a commitment to assure greatest impact of resources, can prevent imprudent service delivery by authorizing appropriate levels, frequencies, and durations of service based on observable client need. In addition, the care coordinator can work for the judicious use of other resources, including willing and able informal caregivers - family members and friends - whose efforts can reduce public costs.

The Area Agencies on Aging Are The Established Vehicles For Implementation Of Local Comprehensive Long Term Care Systems

An Area Agency on Aging is able to provide services far beyond the limited scope of those reimbursed by Medicare, including personal care, homemaker, chore services, home-delivered meals, minor home repair and alteration, electronic monitors, transportation, social support services, as well as health care -- an array of services which would completely confound the Medicare system as it is currently administered. This flexibility, as Area Agencies on Aging have learned, is absolutely essential to an effective community-based long term care system and requires a strong local care coordination structure to make it efficient and effective.

Some proposed long term care legislation has included care coordination (or case management) as an important access service to be added to facilitate in-home care and monitored through the established Medicare evaluation system as home care would be. Care coordination is, more accurately, an administrative function separate from in-home services, integral to local reimbursement and quality control procedures, and capable of ranging across a variety of settings (including institutional ones). Because of the fiscal and monitoring authority of care coordinators, there exists between them and providers an unavoidable and necessary tension essential to good service delivery. If incentives and roles of care coordinators and service providers are designed similarly in legislation, and the existing paper review mechanism is used for cost containment and quality control, the structure will invariably founder. Care coordination is different from services in the continuum of care. It is the local linchpin for community-based long term care systems.

Area Agencies on Aging, in keeping with the intent of the Older Americans Act have developed care coordination to give shape and direction to local long term care in over half of the states. Increasingly, state Medicaid agencies have used the Area Agencies on Aging's care coordination for Medicaid home care waiver programs, and Area Agencies on Aging have been able to integrate the Older Americans Act and Medicaid systems.

Regardless of the mechanism Federal policy makers will use to administer a national long term care service system, Medicare or Medicaid, any effective system will have a local care coordination component. Area Agency on Aging care coordination efforts on behalf of individual older persons parallel, complement, and enhance the Area Agency on Aging's community-wide coordination efforts through planning, contracting, agency conferencing, and general advocacy. It would seem altogether fitting that the Area Agencies on Aging, with by far the largest extant system experienced in coordinating home care, both on the individual and community levels, be the Federal vehicle through which a national comprehensive long term care system is operated.

To create another system to perform what the Aging Network is fully capable of doing, rather than adopt the existing Area Agency Network, would not only be wasteful, but would also isolate the programs of the Older Americans Act from the long term care system of which the Act instructs them to be a part and jeopardize the substantial state and local funding Area Agencies on Aging have drawn into their local systems of services.

Principles For Long Term Care Legislation

Whether the emerging long term care system is to be directed from the Federal or from the state level is beyond the scope of this paper, but, regardless, to assure that the system will be in line with our fundamental social values and will facilitate public understanding and utilization, it should rest on sound principles:

1. The system should be client-centered, and managed by a non-biased care coordinating agency.

All too often specific reimbursement systems limit service delivery systems to a narrow range of services, such as health services, or to a particular set of providers, such as licensed medical agencies, or to a specific setting, such as nursing homes. The net effect is to force at-risk persons with a wide variety of conditions and disabilities into a narrowly focused regimen which will frequently give inadequate support or will demand such restriction that a client's independence and dignity are sacrificed.

A non-service-providing care coordinating agent with flexible fiscal authority can tap into the broad range of services available through diverse providers to tailor care to a client's demonstrated need. Health care, social support, and environmental support can be purchased as needed on the client's behalf. The care-coordinating agent should also manage the client's care in the home, the nursing home, elder housing, the adult foster care home, and the adult day care center.

2. The System Should Provide Universal Eligibility

In eligibility, benefits, and costs long term care should be age-neutral. Although ninety percent of potential long term care clients are over sixty years, disability is no respecter of age. Many Area Agencies on Aging, operating under Medicaid waivers, routinely serve younger clients.

Long term care should also be disease-neutral, focusing on eligibility based on disability rather than the affliction which precipitated it. Physical, cognitive, and mental dysfunctions all can prevent adequate performance of activities of daily living, and although care plans may differ appreciably, eligibility for help should not. There should, of course, be clear standards for eligibility. An assessment should be made of on-going performance of the activities of daily living which can be seriously affected by memory loss and other symptoms of dementia. Being a safety hazard to oneself is surely a valid criterion for eligibility.

Long term care should also be income-neutral. Second only to the fear that disability means leaving home is the fear that disability means spending down to impoverishment. Long term care should be available to all regardless of income, and, while permitting affordable deductibles and cost-sharing, should require no one to become impoverished to become eligible and should not preclude reasonable opportunity for institutionalized persons to return to their communities.

3. The Long Term Care System Should Link With Other Systems

While the care interventions and reimbursement structures of the current Medicare program differ markedly from those in a comprehensive long term care system, they have in common concern for the vulnerable older person. The care coordinator must be alert to client acute care needs and be prepared to provide speedy access to the acute care system. Quick intervention when a disease is precipitating disability can go far in preventing the substantial loss of personal independence.

The care coordinator should also link up with the nursing home ombudsman, transportation systems, and legal services readily available through the

contracted services of the Area Agency on Aging. The care coordinator should also be in continual contact with the planning operations of the Area Agency on Aging to be involved with developing appropriate services and settings. And the care coordinator should work closely with the network of the client's family and friends, not only apprising them of developments and options, but also supporting, encouraging, and even training them as caregivers. Families can not only save money by helping, but they also can give the afflicted family member love and moral support.

4. The Long Term Care System Should Have Clearly Delineated Lines of Responsibility For Insurers And Levels Of Government Administration

The most recent literature indicates that the private insurance industry will not be able to market comprehensive long term care policies which will be affordable to more than a quarter of the nation's elders. Therefore, it is likely that public insurance will provide the broad base of support for the system. There is a danger in the rush of the private insurance industry to build a mechanism for a clientele parallel to the public one for the majority of functionally disabled. This could cause a two-tiered system or a constant restructuring of private policies. It may be more reasonable that the private insurers provide coverage of supplementals such as deductibles, co-pays, and extra amenities to avoid competition with the publicly-subsidized services. In this way, clients would utilize a single care coordinating system with a single system of eligibility, avoiding the inevitable bewildering fragmentation that comes with an array of eligibility requirements, with clients bouncing from system to system.

Client shifting also can result if the Federal and state roles are not clear. It is not in the scope of this paper to explore which level should carry the primary administrative role, but if the states have the lead, policy should eliminate those conflicting cost-sharing incentives which now encourage the states to "dump" clients into the federally subsidized Medicare acute care system or the Federal system to "dump" into the Medicaid nursing home system. Vulnerable clients ought not to be pawns. Further, there should be no differences in state cost-sharing by care setting. The at-risk person's care in the least restrictive setting should be the driving criterion.

In 1973, through the Older Americans Act, Congress purposefully mandated Area Agencies on Aging to establish local long term care systems. It is time to integrate either Medicare or Medicaid with these Area Agency on Aging systems to realize a truly comprehensive, and coordinated long term care system. Medicare, Medicaid, and the Older Americans Act developed separately, but their functions are neither mutually exclusive nor incompatible. Through the Older Americans Act forward-looking policy-makers have already created the local foundations for a national comprehensive long term care program. Regardless of the vehicle used to reimburse - Medicare or Medicaid - fashioning a solid system is a matter of incorporating the reimbursement structure with the tested local systems and services operated by the Area Agencies on Aging.

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ELDERCARE IN THE WORKPLACE

BY

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III. OPTIONS FOR ELDERCARE

Employee caregivers are jugglers. They are serious, responsible employees at their paid worksite. And at home they provide additional hours caring for aging relatives. Some employee caregivers also have dependent children. In discussing the balance of work and caregiving, Linda Rhodes wrote that "sometimes you aren't able to control what's placed on the scales." Currently head of the cabinet-level Department on Aging for the Commonwealth of Pennsylvania, she had the experience of being mother to a newborn and primary caregiver in her home to her husband's frail elderly grandmother, while employed. Employers can play a key role in helping employees balance the scales by developing policies and programs that address the needs of elder caregivers.

Some employers have begun to respond to this plight. The policies and practices that companies are using reflect several things: 1) employee needs; 2) assessment of the relationship between work and family life; 3) organizational needs; and 4) the decision-making process. In a 1986 Conference Board study of corporate decision-making for supportive family policies, author Dana Friedman suggests the following options as "work and family solutions":

- creation of supporting services,
- providing counseling and referral services,
- offering financial assistance,
- easing time constraint,
- donating to community services, and
- accommodating major transitions.

These solutions provide a helpful framework for reviewing corporate eldercare initiatives. Before considering eldercare alternatives, however, there needs to be some consideration of caregiving.

WHAT DO CAREGIVERS DO?

Caregiving is a two-part endeavor. First is the actual **provision of care**. The older person may need assistance with personal care such as toileting, bathing, and feeding, or other everyday things like shopping and transportation. In addition to these "activities of daily living" (ADLs), there are other essential tasks necessary to running a household of any size. These activities, referred to as "instrumental activities of daily living" (IADLs), include things like banking and bill paying, home maintenance and repair, correspondence, household records, health and medical appointments.

The second part of caregiving is **managing this care**. This involves helping determine what the elder can and cannot do, what the primary caregiver can do to help and what help is needed from others. It involves arranging for some or all of this help from others, and continuously monitoring the situation.

While this two part description explains the kind of activities involved in caregiving, it doesn't tell the whole story. Employee caregivers spend much time providing companionship and emotional support for their elders.

WHAT DO EMPLOYEE CAREGIVERS NEED?

All caregivers are faced with some of the same concerns and develop similar stresses. A primary stress is finding the necessary help for their frail relatives. Caregivers need **information on community services**, including home care for older people, and professional services such as assessment and case management. The need for information is often considered a bigger issue than the money to pay for the services.

In addition to information about sources of help, employee caregivers need **help understanding the nature of the situation** they are in, and the skills to help their elder relative satisfactorily. For this they need knowledge about the normal aging process and the care of frail older people.

Employee caregivers need a **break from their caregiving responsibilities**. The research shows that some working caregivers are providing as much as a full work week as caregivers in addition to a full week on their paid full-time job. Respite programs are one response to this need. Through a respite service, a caregiver can arrange occasional or regular relief. There are programs in which substitute caregivers come into the older person's home, and ones in which the older person goes to stay at a care facility. The respite may be for the primary caregiver to get a vacation or just a day off.

Employee caregivers need **recognition of their situation**—not for a pat on the back but for a fair response from supervisors. Some eldercare problems need attention

during work hours and may require time away from the worksite or on the telephone. Employees may or may not know all their eldercare problems in advance because some occur suddenly. They may vary in urgency but still require immediate attention.

HOW EMPLOYERS DEVELOP AN ELDERCARE PROGRAM.

There is no single "best package" for eldercare. Successful eldercare programs respond to employee needs, the employer's needs, and the nature of the organization and environment. A good assessment process is necessary to determine a course of action. This includes analyzing the personnel benefit package and looking at leave policies, workloads, schedules, and telephone usage policies.

• TRAVELERS

In 1985, The Travelers Corporation, the Hartford based insurance and financial services giant, conducted a pioneer survey among home office employees age 30 and older to learn the nature and extent of their eldercare responsibilities and how this affects their lives. The survey showed that 8 percent of the employees who care for an elderly relative spend 35 hours a week or more doing so and that approximately 20 percent of the employees surveyed were providing some kind of assistance to an elder.

Travelers used their comprehensive study to help develop an eldercare program with many components: counseling, information, flexible scheduling, and the addition of aging dependents to its flexible benefits program. Mini-profiles of Travelers and a dozen other corporate initiatives are included in Issues for An Aging America: Employees and Eldercare, a briefing book prepared by the University of Bridgeport and available from The National Council on the Aging (600 Maryland Avenue SW, Washington, DC 20024).

• STATE OF ILLINOIS

State government in Illinois is active in employee caregiving as an employer and as a resource on caregiving that addresses caregiving problems beyond the scope of the workplace. On the one hand, the Illinois Department on Aging (IDOA) has had eldercare education efforts with companies such as Blue Cross/Blue Shield, Donnelley Directory, Illinois Bell and Ameritech Publishing of Illinois. On the other hand, it is using its own and other state resources to address the eldercare issue for all state employees. It is developing a database on public employee caregiving by surveying state employees about their eldercare needs.

IDOA has done this by adapting the Travelers employee survey to their situation. They provided the survey instrument and a summary of findings from IDOA's survey of its own employees to other state agencies who were asked to duplicate the survey, distribute it, tabulate results in the same format, and return them to IDOA. Sixteen state agencies participated. Illinois obtained valuable findings about the extent and level of employee caregiving for older people. Another notable finding appears to be the high proportion of total employees who anticipate caregiving responsibilities in the near future. Currently, IDOA is working on a comprehensive response with the state Department of Central Management Services. An immediate result was two caregiver fairs, one in Springfield and one in Chicago, in September 1988.

ELDERCARE STRATEGIES

The most frequently used eldercare strategies are providing information and education and easing time constraints. What follows are examples of some of the benefits or services developed in relation to particular strategies. The program mentioned may be the company's only effort, one of a few activities in that organization, or one element of a comprehensive eldercare or work/family initiative. These examples are selective and do not represent the only companies offering the particular benefit. Many of these examples are taken from a more extensive compendium of Public/Private Partnerships in Aging by the National Association on State Units on Aging and the Washington Business Group on Health. This compendium is available from NASUA (2033 K Street NW, Suite 304, Washington, D.C. 20006).

• INFORMATION AND EDUCATION

PepsiCo developed an extensive eldercare resource guide focusing on three subjects: normal aging; physical and mental health; and finding help. **Travelers** conducted a caregiver fair gathering representatives from the corporation and more than 20 service provider agencies to answer questions and provide information on available community services. **Pitney Bowes, Ciba Geigy** and **Mobil** have provided informational forums at the workplace on such issues as the aging process, service delivery systems, and specific aging disorders. **McNeil Consumer Products** provided packets of resource information for Employee Assistance Program personnel.

• COUNSELING, SUPPORT AND REFERRAL

IBM has implemented in 1988 a nationwide eldercare consultation and referral service for employees and retirees for themselves or their family members. Referrals are made to community based agencies, some of which are publicly

supported Area Agencies on Aging and the service providers they fund. The IBM model has been adopted in 1988 and 1989 by other companies such as **Aetna Insurance** of Hartford, Connecticut.

In 1988, the **Social Security Administration** began testing a model eldercare support program in the Atlanta region. Likewise the U.S. Office of Personnel Management have established an information and referral service. The University of Bridgeport conducted a hotline program used by **PepsiCo, People's Bank** of Bridgeport and **Remington**. This hotline was a confidential consultation service staffed by professionals at the university, weekdays 8:30 A.M. to 4:30 P.M.

Counseling through Employee Assistance Programs is available at **Levi Strauss** and Co., **Honeywell**, and **Blue Cross and Blue Shield** of Indiana. **Pitney Bowes** has offered support groups at the worksite and **Steelcase Inc**. provides informal support groups through the Retiree's Club. Support groups are appropriate both for older people and for caregivers. They provide a place to blow off steam and get practical help about personal situations from others in similar circumstances.

• EASING TIME CONSTRAINTS

In a national study of state governments as employers, the National Association of State Units on Aging and the International Personnel Management Association found that the use of sick leave and extended unpaid leave for the purpose of caring for an aging dependent is widely available as official personnel policy. The quantity of sick leave that can be used for dependent care ranged from 3 to 30 days. One state allows employees to use all accrued sick leave for this purpose and another allows use of advance leave—that is, what the employee is expected to earn within the fiscal year.

Another practice is granting unpaid leave for a given period with the guarantee that the employee's job or one of comparable worth will be protected for a given time period. This is provided by statute in some states and is the subject of bills in many state legislatures and Congress (see section on Legislative and Regulatory Environment for Eldercare). This practice was also widely reported. The duration of the leave period ranges from 80 hours to two years with the vast majority at one year.

The federal bills provide for the employer to continue paying the employee health benefits. For the most part, state employers reported that some or all benefits are curtailed for unpaid leave. Some will continue health coverage if the employee pays the employer share. Two states allow the employee to continue accruing vacation and sick leave up to 30 days. Two states allow use of already accrued leave at the beginning of a pay period for the purpose of retaining benefits. One state reported their Non-Industrial Disability Law can be used for eldercare. One state reported that all benefits are retained.

At **Pitney Bowes, Inc.** there is flexible leave for family emergencies as well as arrangements to change work shifts as needed. **Atlantic Richfield** offers six paid days off for tending sick family members. **People's Bank of Bridgeport** offers leaves of absence to employee caregivers and **Champion International** expanded their 6 month leave of absence provision to include eldercare. **Travelers** has flexible schedules. In 1988, **IBM** announced a leave of absence policy allowing for leaves of up to three years for dependent care.

• OFFERING FINANCIAL ASSISTANCE

Remington subsidizes respite care for their elder caregivers by picking up half the cost of a home aide or a senior companion provided through the greater Bridgeport Visiting Nurse Association on weekend or evening hours. However, this program has not drawn extensive response to date.

Employers can make available to employees tax advantaged benefit programs. Section 129 of the Internal Revenue Code permits employers to offer Dependent Care Assistance Plans (DCAPs) as a nontaxable benefit for employers and employees as part of their flexible benefits plan. However, the restriction that the older person must be a dependent of the employee for tax purposes, has severely limited the use of DCAPs for eldercare. At **PepsiCo**, the Choice Pay Reserve Account may be used to pay for health care and nursing care expenses for dependent elders in some situations.

For a detailed discussion of Dependent Care Assistance Plans, the Federal Dependent Care Tax Credit and State Dependent Care Tax Credits, see the section on the Legislative and Regulatory Environment for Eldercare. **Ford** and **General Motors** are testing a new type of benefit: long-term care insurance at home for in-home nonmedical custodial care for employees or retirees. This is the first employer financed program of its kind but it is at present severely limited in scope.

• CREATING OR SUPPORTING DIRECT SERVICES

Stride Rite is expanding an existing child day care center at the work site to create an intergenerational day care center due to open in early 1990.

These strategies are options for employers who want to secure a stable and productive workforce. They support

the American tradition of individual responsibility in a peculiarly American way— by providing help that enables the employed caregiver to carry out all her roles in society.

RESOURCES ON ELDERCARE

A variety of public and private organizations on the national and local level offer help to all kinds of employers on eldercare.

• STATE AGING NETWORKS

The 57 State Agencies on Aging and their 672 local Agencies on Aging represent a major source of help. Because they are mandated under federal law to ensure reasonable access to services by all older people, these agencies have developed extensive systems of information and referral for the elderly and their family members across the country. Over 30 states operate statewide 800 numbers for information and referral and many states also maintain 800 hotlines for crises, elder abuse, and nursing home complaints.

These state aging networks are responsible for planning and coordinating statewide systems of community based services for the elderly, designed to assist older people to remain independent in their own homes and communities—thus avoiding or delaying unnecessary institutionalization. The aging network offers employers a broad range of assistance not otherwise available from a single source. The Directory in the Appendix contains the names, addresses, and phone numbers of the State Agencies on Aging.

• THE NATIONAL COUNCIL ON THE AGING

NCOA represents aging service providers and professionals across the country. It participated in the National Conference on Issues for an Aging America: Employees and Eldercare. NCOA distributes a briefing book for executives on eldercare issues and solutions (Creedon, 1987). Its membership divisions include an organization for family caregivers. The Family Caregivers unit provides a regular newsletter to caregiving families and also an 800 number with technical consultation capacity. It offers a resource list for respite care. NCOA has many publications on caregiving for the elderly including: Family Caregiving Guides; Ideabook on Caregiver Support Groups; Support for Family Caregivers of the Elderly: Highlights of a National Symposium and Caregiving Tips. NCOA also offers consultation to corporations on eldercare and develops support programs for corporate use.

• THE NATIONAL ASSOCIATION OF STATE UNITS ON AGING

NASUA represents the 57 state and territorial government agencies charged with advancing the social and economic agendas of older persons in their respective jurisdictions. NASUA has many publications on eldercare including: "Building Responsive Systems for Public Employee Caregivers–Eldercare Policy and Program Options"; "State Initiatives for Public Employee Caregivers"; and "Tools for Assessing Employee Caregiver Needs", a package of employee surveys which can be used or adapted by employers.

NASUA has worked extensively with the Washington Business Group on Health and the International Personnel Management Association in developing models and promoting partnerships between State Agencies on Aging and public and private sector employers. NASUA refers employers within a single state jurisdiction to the appropriate State Agency on Aging for assistance with eldercare. However, for companies with employees in multiple states or with a significant number of long distance caregivers, NASUA can provide direct access to all state aging systems and has the unique capacity to liaison for employers.

NASUA and the Illinois Department on Aging are testing a prototype—ELDERLINK—a national 800 telephone access system for linking caregivers living anywhere in the country to services in the community where the older family member resides.

• AMERICAN ASSOCIATION OF RETIRED PERSONS

AARP offers a package of books called "Caregivers in the Workplace" and many consumer materials on problems of frail older people. AARP has developed a Caregiver Fair packet for workplace use and has sponsored extensive research on eldercare issues.

• The **NATIONAL ASSOCIATION OF AREA AGENCIES ON AGING** has a special report on eldercare and assists caregivers through the Area Agencies on Aging.

• The **WASHINGTON BUSINESS GROUP ON HEALTH** has a special program on aging in the workforce and offers technical support on eldercare and other workplace programs through its Institute on Work and Aging.

V. PROGRAM MODEL VARIATION

Eldercare as an employee benefit is often discussed in relation to child care benefits because they share some similarities. There are differences as well. Consideration of eldercare program models requires an understanding of the kind of care involved in eldercare.

In contrast to child care, eldercare is not associated with provision of full-time day care. Rather it encompasses various possible solutions that reflect the range of needs and conditions of older people. While there is such a service as adult day care, it is intended for extremely frail older people. These older people are a small proportion of dependent elderly, not the only portion of the elderly population of concern to employee caregivers. Adult day care centers therefore are not the same kind of main event in eldercare that child day care centers are in the child care field, though they may be relevant for some 25 percent of the dependent elderly and their caregivers.

Aging relatives may live nearby or at long distances. Even relatives who are heavily dependent on family members for support and assistance may not live with those family members. While usually there is a primary caregiver, responsibility for providing assistance to an older person may be shared among spouses, children and other family members. The kind of care needed by an older person may be physical assistance at home to get around, or it may be personal care, emotional support, and/or organization and management. Eldercare may be needed by both parents or by more than one grandparent at a time. If aunts or uncles or other relatives have no children of their own, the responsibility for their care may fall to a niece or nephew. Thus the person(s) needing care and those providing it may form quite different family constellations.

There are other differences as well. The elders of concern to employee caregivers have an age range of more than 40 years—approximately 60 to 100. They also have a lifetime of experience caring for themselves and for others. They, not their caregivers, have the authority for their own decision-making. Unless they are in a protected status determined in the court system, they have the right to accept or reject the help arranged by the caregiver.

Children require total care for predictable periods. In the normal course of events there are positive milestones in growth and development. Some aging relatives need only a modest amount of help but on a regular basis, while others may need intensive support for a limited time or for the long term. The outcome may be positive—often due to the help provided by caregivers. But it may not, and the caregiver must deal with the emotional upheaval of an older person's lost or decreasing capacity.

CURRENT DIRECTIONS IN ELDERCARE IN THE WORKPLACE

There is increasing awareness of the number of employee caregivers of older relatives and of the wisdom of using the workplace site for eldercare assistance. Currently, the major strategies are needs assessment, easing time constraints, accessing services, and education and counseling. Less attention has been given to financial benefits. Direct provision of services has not been a major strategy. Some employers oversee many eldercare related benefits and services as part of a comprehensive approach. Others may sponsor a single activity only. All of these initiatives are listed below along with related materials and/or resources for each.

• ADULT DAY CARE

These programs help mentally and physically impaired adults live in the community, maintain or improve their level of functioning and provide relief and assistance for employee caregivers of frail elderly (and younger disabled adults). The "how to" manual for establishing, organizing and managing adult day care centers is ***Developing Adult Day Care: An Approach to Maintaining Independence for Impaired Older Persons*** by The National Institute on Adult Daycare, a professional unit of The National Council on the Aging, Inc. (600 Maryland Avenue Southwest, West Wing 100, Washington, DC 20024).

• NEEDS ASSESSMENT

A major initiative has been to determine the level and nature of employee caregiving responsibility. This has involved surveying employees and surveying employers. In addition, there has been effort to analyze the situation and conditions of the workplace regarding caregiving.

• EMPLOYEE SURVEYS

The Travelers Company developed and administered an employee survey in 1985. This pioneer survey has been a model for several others. Employee surveys have been

developed by AARP, University of Bridgeport Corporate Eldercare Project, Case Western Reserve University School of Applied Social Sciences, Metropolitan Chicago Coalition on Aging, and National Association of State Units on Aging/Washington Business Group on Health Corporate Involvement with Aging Project. ***Tools for Assessing Employee Caregiver Needs: Public/Private Partnerships in Aging*** is a collection of five employee surveys including the Travelers, Bridgeport and Chicago ones mentioned above available from National Association of State Units on Aging, 2033 K Street NW, Suite 304, Washington, DC 20006.

New York Business Group on Health, Inc. surveyed a sample of companies with respect to their awareness of and attitudes toward the problems of employee caregivers and published the results and the survey instrument in January 1986. It is called, ***Employer Support for Employee Caregiver*** (available from NYBGH, Inc. 622 Third Avenue–34th floor, New York, N.Y. 10017). The Bureau of National Affairs has also recently surveyed employers on these issues (February, 1989).

A mail survey on eldercare was sent to 1,500 employers across the country by the National Association of Area Agencies on Aging as part of a project funded by the Administration on Aging of the U.S. Department of Health and Human Services (Award #90 AM0158). An employer survey was conducted by Lenore Kola, Ph.D., Associate Professor, Case Western Reserve University School of Applied Social Sciences, 2035 Abington Road, Cleveland, Ohio 44106.

• EASING TIME CONSTRAINTS

There are many examples of leave policies to accommodate caregivers of elderly relatives and other, though fewer, examples of rearranging work for this purpose. The Travelers Companies has flexible schedules. At Pitney Bowes, Inc. there is flexible leave for family emergencies as well as arrangements to change work shifts as needed. Atlantic Richfield offers six paid days off for tending sick family members. People's Bank of Bridgeport offers leaves of absence to employee caregivers. Champion International expanded their 6 month leave of absence provision to include eldercare in 1987 and in 1988, IBM established a policy providing up to three years leave to caregivers.

Use of sick leave for eldercare is widely available as official personnel policy in state government according to a 1988 study by the National Association of State Units on Aging and the International Personnel Management Association. The quantity of sick leave that can be used for dependent care ranged from 3 to 30 days. One state allows employees to use all accrued sick leave for this purpose and another allows use of advance leave—that is, the amount of leave the employee is expected to earn within the fiscal year.

The practice of granting unpaid leave for family care responsibilities for a certain amount of time with job protection is a personnel benefit provided by some employers. It is provided by statute in an increasing number of states, usually covering employers of a given size. The Maine statute is an example of a state family/medical leave law including eldercare.

Bills on family and medical leave are under Congressional consideration. The information packet entitled ***Family and Medical Leave*** contains research data, case studies, and public policies on leave policy and dependent care. It is available from the Media Consortium, 1333 H Street Northwest, 11th floor, Washington, DC 20005.

• ACCESSING SERVICES

The vast majority of older people live independently and enjoy fruitful lives in relative good health. There is also the reality of the aging process. Levels of functional disability do occur and where they exist, they range from slight to severe. Loss of some capacity may occur gradually or suddenly. In any event, when it occurs there is a need to determine exactly what is happening and why, what can or should be done, and what resources are available.

Most older people confronting such a situation have little experience using the formal system of helping services. In fact, most older people and their adult children are not aware of the existence of the system of social and community services— including diagnosis and treatment therapies for aging adults— that has existed in the public and private profit and non-profit sector for decades. When there is any kind of loss of ability, there is an almost universal need to be aware of these services and to know how to use them.

Providing information about existing services and assistance in using them is an important strategy for eldercare support programs in the workplace. Access to a lot of information in one place results in substantial time savings for an employee caregiver—time that otherwise has to be spent by each employee in this situation during business hours when agencies and professionals are available. The process occurs through several activities in the workplace.

—ELDERCARE RESOURCE GUIDES. Written handbooks or guides, such as the one prepared for PepsiCo by the University of Bridgeport Center for the Study of Aging (Creedon and Wagner, 1986), are one means employers use for informing employees about needed

sources of help. The PepsiCo guide includes sections on normal aging and on physical and mental health as well as a section on services. (PepsiCo, Inc., 700 Anderson Hill Road, Purchase, New York 10577). Such handbooks are now in use at Champion International, Consolidated Edison, Boehringer Ingelheim, and IBM.

—CAREGIVER FAIRS. These events consist of providing an opportunity for large numbers of employees to learn about many products and services at once. The sponsor arranges for representatives of service provider agencies to gather at a suitable place and time—preferably at the worksite during hours employees are available. Tables and chairs are set up so there are places to talk about their services and hand out written materials. The Travelers Companies and the State of Illinois are large employers with recent experience conducting caregiver fairs. The AARP package called ***Caregivers in the Work Place*** includes a pamphlet on a caregivers fair (AARP, 1909 K Street Northwest, Washington, DC 20049).

—INFORMATION AND REFERRAL SERVICES FOR OLDER PEOPLE. The publicly funded state/local aging network provides an extensive information and referral (I&R) system for older people. The federal Older Americans Act requires that State Units on Aging divide the states into "Planning and Service Areas" and that Area Agencies on Aging covering these PSAs use a portion of Older Americans Act dollars to support information and referral services. In this way, the nation's 672 Area Agencies support various forms of I&R covering the entire country. Additionally, over 30 State Agencies on Aging have statewide 800 numbers for information and referral to aging services.

An area's I&R may be a "stand alone" model which serves only older people or part of a generic I&R which addresses all age groups and subjects. Usually there are staff with specialized training on aging and older people's needs. Information and referral services are equipped to respond to inquiries from individuals and community agencies. They help older people, family and friends move through the system to obtain needed help, and follow-up to determine if additional assistance is required.

—LONG DISTANCE CAREGIVING. Since there are State and Area Agencies on Aging covering the whole country, the state/local aging network has the capacity to respond to long distance caregiving. A family member or friend can access the system in their own geographic area to generate a response in another area of the country where the older person lives.

—STATEWIDE HOTLINES. In addition to I&R services in every Planning and Service Area, over 30 states have a variety of 800 telephone hotlines for information and referrel, elder abuse, nursing home complaints, information about Alzheimer's disease, for processing Medicare claims and for information about paid prescriptions. For the most part, these are in-state 800 numbers, but Illinois has a nationwide 800 number for inquiries about services in that state or to connect caregivers to other state systems where older relatives reside. In all cases, the State Unit on Aging in every state can explain how to contact the appropriate information and referral service. (An Aging Network News reprint of ***State Aging Profiles*** includes all the statewide hotlines and is available from NASUA, 2033 K Street N.W., Suite 304, Washington, DC 20006.)

—PRIVATE INFORMATION AND REFERRAL NETWORKS. Private for-profit and not-for-profit organizations have developed information and referral networks, usually targeted to specialized audiences. Aging Network Services is a for-profit national network of geriatric care managers in which a central office provides an introductory consultation, linkage of the client with a member of their network of social workers and follow-up. The Center on Aging at the University of Bridgeport provided an eldercare hotline for several corporations during its experimental research project. Currently such organizations as Work/Family Directions, Inc. of Boston and The Partnership Group of Landsdale, Pennsylvania offer nationwide I & R referral services.

The non-profit Elder Support Network is sponsored by the Association of Jewish Family and Children's Agencies. It acts as a link between individuals, their distant families, and the participating Jewish Family Service Agency which provides direct services to the aging relative. IBM, using Work/Family Directions, has established a national eldercare consultation and referral service for employees and retirees for themselves or their family members as a prepaid employee benefit. Referrals are made to community-based agencies, some of which are publicly supported Area Agencies on Aging and the service providers they fund. The National Association of Private Geriatric Care Managers publishes a directory of member professionals who provide care for older people (NAPGCM, Box 6920, Yorkville Station, New York, NY 10128).

—INFORMATION AND REFERRAL SERVICE OPERATIONS AND TRAINING. Industry standards for operation of I&R services, as well as training opportunities, directories and technical assistance materials are available from the Alliance of Information and Referral Systems (AIRS). This is a membership organization of I&R providers. (AIRS, 47 S. Pennsylvania Avenue, 4th floor, Indianapolis, Indiana 46204).

—VIDEOTAPE ON INFORMATION AND REFERRAL. ***Ask Me*** is a drama about helping people by using an information and referral service. It is about a family in crisis because the elderly mother is ill and the family does not know what to do. It shows how I&Rs help. The particular model of I&R is a library-based one. It is operated by trained volunteers together with library and social work interns. The video is a project of the Adelphi University School of Social Work and is available on Beta, VHS or 3/4" format (Adelphi University, Vice President for Distribution, Adelphi Productions, Blodgett Studio, Garden City, NY 11530).

• EDUCATION AND COUNSELING

In addition to information on and referral to aging services, another eldercare in the workplace strategy is education and counseling. This may take the form of counseling on a one-to-one basis, seminars on various aging and caregiving topics, and support groups. Support groups are appropriate both for older people and for caregivers. They provide a place to blow off steam and an opportunity for self-help from others in similar circumstances. Support groups can be structured as a self-help activity, or they can be led by professionals with expert background.

There are many examples of these in the workplace. For example, counseling through employee assistance programs is available at Levi Strauss and Co., Honeywell, and Blue Cross and Blue Shield of Indiana. Pitney Bowes, Peoples Bank, and Remington have offered support groups at the worksite and Steelcase, Inc. provides informal support groups through the Retiree's Club.

—CURRICULUM MATERIALS. There are substantial resources available for use in workplace seminars for employee caregivers about older people and their families. Much has been developed for an audience of family caregivers whether they are employed or not. Another source is the large amount of material developed for families of victims of Alzheimer's disease which deal with the role, skills and problems of being a caregiver. The National Council on the Aging, AARP and other organizations can help.

• ALZHEIMER'S SUPPORT GROUPS

—Alzheimer's Family Support Groups: A Manual for Group Facilitators, Volume III, 1984 (Suncoast Gerontology Center, Box 50, 12901 North 30th Street, Tampa, FL 33612, supported by U.S. Department of Health and Human Services, Administration on Aging Grant #90-AT-2157) was prepared to assist coordinators and facilitators of all backgrounds in understanding Alzheimer's disease and in the development and on-going maintenance of Alzheimer's family support groups.

—The Ideabook on Caregiver Support Groups (National Council on the Aging, Inc. 600 Maryland Avenue SW, Washington, DC 20024). This comprehensive guide to caregiver groups also includes a directory of nearly 300 caregiver groups around the United States.

—A Manual for the Development, Implementation and Operation of Family Support Groups for the Relatives of Functionally Disabled Elderly, was developed by Christopher L. Hayes, Michael A. Creedon, Project Director, Center for the Study of Pre-Retirement and Aging, The Catholic University of America, (1984) under a grant from Virginia Department for the Aging (700 East Franklin Street, 10th floor, Richmond, Virginia 23219-2327). This is an in-depth look at the development, planning, and implementation of family support groups for relatives of functionally disabled older adults. It is intended to provide the necessary technical knowledge to start a family support group.

• RESOURCES

"Caregiver Education and Support," Parent Care Resources to Assist Family Caregivers Vol. 1, No. 6, Sept/Oct 1986, (Gerontology Center, The University of Kansas, Lawrence, Kansas 66045) is a collection of three dozen resources on the subject of caregiver education and support. Each resource is explained in separate one page descriptions. An extensive bibliography is also included. Topics include: skills for group leaders; what makes a support group successful; what should be the focus of support groups; workshops; caregiver's manual; training manuals for professionals; books to recommend for families; and advocacy information among many others.

—Training Caregivers. Caregivers Practical Help—A Six Session Curriculum for Informal Caregivers, Instruction Guide for Course Leader and Informal Caregivers Participant Manual, New York State Office For The Aging in cooperation with the New York State Education Department (Office for the Aging, New York State Plaza, Agency Building #2, Albany, New York 12223) is intended to help those currently involved in caregiving and for family members, friends or neighbors who are potential caregivers at some future time. It is also appropriate for older people who want to learn about themselves, their peers and the aging process.

—Educational Seminars Planning Guide and Trainer's Manual, part of the AARP Eldercare in the Workplace booklets (1909 K Street Northwest, Washington, DC 20049) provides content material and "how to" tips for topics including stress, stress and time manage-

ment, caregiver feelings, expected changes in aging relatives, family decision-making, informal and formal support, coping with an aging relative's mental changes, tips on personal care, housing and independence and legal considerations.

—***Older People and Their Families: Coping with Stress and Conflict***, 1987, (Center for the Study of Aging and Human Development, Duke University Medical Center, Durham, North Carolina 27710) is a unique educational package that can be used as a one-time program about intergenerational communication in families or coping with stress and conflict in older families. The focus is on families not typically perceived as "at risk". The materials cover conflicts generated by shifts in dependency (including recent or revived dependency of adult children), by shifts in role expectations (perhaps generated by illness) and by shared living situations. Designated areas of conflict separate the sources of conflict from the emotional reactions of both family dyads and individuals in a family. The materials emphasize the importance of taking the role of the other in coping with a conflict.

—***Rhode Island Caregivers—Caring: A Training Program for Family Caregivers***, (Rhode Island Department of Elderly Affairs, 79 Washington Street, Providence, Rhode Island 02093) is a training program for caregivers offering a practical approach to caregiving and a realistic view of the aging process. It was designed to clarify problems confronting caregivers of older people, to serve as a basic source manual, and to provide resource information that can be continually changed and updated.

—***Family Seminars for Caregiving: Helping Families Help***, 1984, (Pacific Northwest Long-Term Care Center and Institute on Aging, University of Washington, Seattle, Washington, supported by U.S. Department of Health and Human Services, Administration on Aging #90-AM-0046/02) is a series of family seminars consisting of two hour modules to be conducted weekly for six weeks. The curriculum addresses a wide range of topics including changing family roles, decision-making, normal changes with aging, common illnesses of the elderly, community resources, legal concerns and the importance of self-care. The emphasis is on helping caregivers continue in that role.

—***Instructional Manual for Parent Caring Program, Volume I: The Family Series***, (The College of St. Scholastica Minnesota 55811) funded by the Administration on Aging, is a seven session educational series for individuals who want to learn how to provide better care to an older person. Topics include: psychological, behavioral, and biological aspects of aging, communicating with older people, helping resources, legal rights and financial considerations, the importance of personal relationships in the process of aging, shared decision making about living arrangements and stress management for the caregiver. For each topic there is a statement of purpose, list of objectives, outline, discussion guide narration, bibliography, and participant materials.

- **FINANCIAL BENEFITS**

Through the tax system there is some government support for eldercare. There is a Federal Dependent Care Tax Credit. In 29 states there are State Dependent Care Tax Credits. Also, the federal government gives a tax break to employers who provide financial assistance for employee dependent care. This benefit is called a Dependent Care Assistance Program or DCAP. There are a few instances of employer subsidy of eldercare benefits, and a pilot service credit system patterned on the blood banks developed by the Robert Wood Johnson Foundation.

—**TAX CREDITS**. The federal tax credit allows taxpayers with work-related expenses for dependent care to set off a portion of those expenses against their federal income tax liability. Also, 29 states have dependent care tax provisions. In 23 of these, the provision is tied to the federal credit. Both kinds are explained in ***Dependent Care Tax Provisions in the States: An Opportunity for Reform*** by Lynne Crofton Isensee and Nancy Duff Campbell (National Women's Law Center, 1616 P Street Northwest, Washington, DC 20036).

—**DEPENDENT CARE ASSISTANCE PROGRAMS**. Under Section 129 of the Internal Revenue Service Code, the federal government allows employers to provide employees with up to $5,000 in dependent care assistance. It is tax deductible for both the employer and the employee. There are restrictions regarding eligibility, allowable expenses and definition of "dependent" that limit its utility for eldercare. Here are two helpful explanatories:

1) ***Tax-Advantaged Plans for Elder Care*** in the PepsiCo Eldercare Handbook. This two-page summary explains how a private employer uses the Internal Revenue Code provisions to offer plans for employees to set aside money from their earnings, before taxes, to pay for medical and dependent care expenses.

2) ***Dependent Care Assistance Program–State of Illinois.*** This comprehensive consumer brochure explains how "DCAPs" work, answering such questions as: How do I get tax-free dollars? How soon can I begin contributing? How much can I contribute? What happens when my family status changes? Are

all of my dependent care expenses eligible for reimbursement? The brochure also outlines four hypothetical family situations with different family size and number of dependents. Starting with a given annual salary, it explains what is the real disposable income for that family unit using a Dependent Care Assistance Account, compared to using the Federal Dependent Care Tax Credit, and compared to using neither. (Available from Illinois Department of Central Management Services, 600 Stratton Office Building, Springfield, Illinois 62706.)

—**LONG-TERM CARE INSURANCE.** There are private long-term care insurance products on the market today that pay some of the cost of nursing home care and some home health care. For the most part, there is little, limited, or no coverage in these plans for emergency care, respite care, intermittent home health care unrelated to hospitalization or other in-home services, adult day care, or hospice care. As for other kinds of insurance policies, long-term care policies are not sold to people already suffering from severe, chronic, debilitating conditions. Private insurers, especially Blue Cross plans, are beginning to add coverage for home health care, adult day care and other non-institutional services to long-term care insurance policies, according to David Markson, President and Chief Executive Officer of Blue Cross of Greater Philadelphia. This insurance company is currently a partner of the Philadelphia Center for Older People in sponsoring caregiver information seminars in the workplace.

—***Who Can Afford a Nursing Home?*** is a comprehensive summary of currently available long-term care insurance products. It explains how to examine these products in terms of what is and is not covered, eligibility, size, length and timing of benefits, renewability, home care features, relation to Medicare, rate hikes, costs, whether or not it is appropriate to buy such a product, for whom and under what conditions (Consumer Reports, May 1988).

—**SUBSIDIES.** Remington Products, Inc. developed an experimental program through which it will provide $10,000 on a cost sharing basis for respite care. The company pays half and the employee pays half. According to Remington Vice President, Michael Duda, pre-certification is required and each worker will be limited to 95 hours of respite care per year. The Visiting Nurse Association of Greater Bridgeport will do the pre-certifications. The respite is for employees but outside their work hours at Remington. The purpose is to help employees have some free time. The senior author of this monograph has been a consultant on this project.

—**COMMUNITY SERVICE CREDITS.** This concept, modeled on the blood bank, is for volunteers, especially over age 60 "well elderly" to assist frail older people. As the well elderly provide service, they accrue credit hours which are deposited into a personal account to draw on when they themselves are in need of services. Family members and service provider organizations can earn credits to meet future service needs. The Robert Wood Johnson Foundation has provided support for six community service credit demonstration programs. For more information, contact the Robert Wood Johnson Foundation, P.O. Box 231, Princeton, New Jersey 08540.

Aetna
LIFE & CASUALTY

SECTION V

Aetna Life and Casualty recognizes that the world we live in has dramatically changed over the last twenty years. The world in which we sell our products and the employees who work for the Company are more diverse than ever before with a wider mix of ages, experiences and family constellations. The Company acknowledges that in order to continue to recruit and retain our workforce, new policies and services must be developed to support work and family life.

In 1987, Aetna created a Work and Family Task Force to recommend changes to policies which would recognize the impact of work and family on our workforce. By 1988 a special unit was created within the Company to develop and implement programs and policies to support employees and supervisors in balancing work and family responsibilities.

One important issue that has surfaced is eldercare. There is no longer anyone at home to take care of the older family members who may need assistance or help. Everyone is working. Aetna recognizes that employees may struggle to keep their job responsibilities at the same time that their elder needs assistance.

We therefore provide a range of free services to employees as part of their benefit package. Some of these services are:

- Nationwide Elder Care Consultation and Referral which provides consultation, consumer education, information, and referrals to care and service providers through a nationwide network of 225 community-based organizations. Employees call toll-free to the eldercare agency nearest to their elderly relative. This service to employees is provided through our contract with Work/Family Directions, and includes funding for development of new elder care services within local communities which evidence a need.
- Eldercare Seminars during the workday. Topics offered include:
  - The Sandwiched Generation
  - Aging, Everybody's Doing It
  - Solving the Emotional Dilemma of Eldercare
  - Eldercare, Making the Right Choices
  - Eldercare, Paying the Bills
  - Alzheimers Disease
  - Legal Issues for the Elderly
- Eldercare Support Groups at lunchtime.

Other benefits include:

- Dependent Care Spending Account allowing dependent care expenses for elderly dependents to be paid for with salary reduction, untaxed dollars.
- Long Term Care Coverage for the employee and their spouse.

. Family Leave Policy which allows an employee to take an unpaid leave of up to six months to care for an elderly family member.

Benefits targeted for the older worker:

. Retirement Planning Statement: personalized statement of retirement benefits created every other year for employees age 50 and over.
. Retirement Planning Seminar: for employees and their spouses, this free two day seminar addresses life planning, including health, recreation, and emotional issues of retirement.
. Financial Planning for Retirement: this one day seminar covers financial issues such as estate planning and investment options for retirement.
. Graduated Retirement Option: offers the gradual reduction of work hours in the two or three years immediately preceding retirement.
. Rehire Retirees: offer temporary assignment to retirees for up to 100 hours per calendar year with retention of pension.

Submitted by:

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CORPORATE RESPONSE TO EMPLOYEE AND RETIREE ELDER CARE NEEDS

PREPARED FOR THE

SUBCOMMITTEE ON HUMAN SERVICES

OF THE

U.S. HOUSE OF REPRESENTATIVES

SELECT COMMITTEE ON AGING

SUBMITTED BY

J. T. CHILDS, JR.

WORK/LIFE PROGRAMS

IBM, UNITED STATES

PURCHASE, NEW YORK

Introduction

IBM United States based in Purchase, New York, manufactures, distributes, and services computers and office equipment with a work force of approximately 216,000 employees.

- o IBM operates in more than 250 locations in the U. S., many of them small, and about 20 which are major with 4,000 to 10,000 employees.

- o The IBM work force is highly mobile, with many employees having relocated at various times with IBM, thus their older relatives might live almost anywhere in the U.S.

- o IBM has developed a tradition of equality of benefits and services among all U. S. locations; therefore, we looked for approaches which can be implemented nationwide on an equitable basis.

IBM Response to Dependent Care

Workers with child/elder dependents have obligations outside the workplace that must be met in order to function in the workplace. A dependent's problem can cause difficulty with even the most carefully organized schedule, and relocation can be especially complex for the dual-income couple. Increasingly, companies have become aware that employees contribute more on the job if the stressful aspects of away-from-the-job life can be minimized or eliminated.

In order to understand our population better and determine if our programs were in tune with employees' changing needs, IBM conducted a random personnel research study on work/life balance issues of over 4,000 employees in 1986. The survey's response rate (78%) indicated high employee interest in the topic. The survey showed:

- o Approximately 30% of IBM employees have some caring responsibility for an elderly relative; 8% have adult dependent responsibility; and 4% have adult dependents resident in their home.

- o Fifty-eight percent of IBM employees are part of a dual income couple.

- o Thirty percent of IBM employees have children requiring supervision; more than one third of our dual professional/dual earner couples under age 40 indicate their plans to have/adopt a child in the next five years. This is especially useful data since it provides us advance insight into our growing "Sandwich Generation" population and allows us to anticipate/develop programs to meet their needs.

In response to our employees Work and Personal Life Balance needs, a variety of programs have been introduced such as the Employee Assistance Program, Child Care Referral Service, Work and Family Seminars in the "A Plan For Life Program," Adoption Assistance, Special Care for Children, Elder Care Referral Service, enhanced alternative work arrangements, expanded individualized work schedules, extended leaves of absences for up to three years, and a required management training workshop on the critical issue of helping employees balance their work and personal lives. This workshop develops the business case for management awareness of the demographic changes in our society (i.e., movement

of women to the work force/impact on the traditional family structure, and the available caregiver population for child/elderly family members), and the importance of the managers building partnerships with their employees. Our Three Year Personal Leave program is of particular importance because it permits/encourages employees to utilize this time to respond to family needs such as care for a new born child or an elderly relative.

IBM Response to Senior Employee/Retiree

The IBM retiree population currently numbers 40,000. These employees and their spouses retain their eligibility for our A Plan for Life and Employee Assistance Programs. In addition, to ensure a proper communications link exists with our retiree population an 800# staffed by retirees is available each work day. The purpose of this telephone service is to assist retirees with any personal problems or questions. Also, as a retiree you retain your membership in the Quarter Century Club and the IBM Club; thus, providing a continuing social link to the company. In addition, a special retiree newsletter is sent to each retiree's home. A copy of the newsletter, our Health Education program pamphlet and Wellness brochure are included in our information package.

As an enhancement to retirement planning, IBM has the following programs available to eligible employees:

1. Tax Deferred Savings Plan (TDSP) - To encourage financial planning for one's retirement years, employees may defer up to 8% of their salary with IBM matching the first 5% with 30 cents for each dollar contributed by the employee.

2. Responding to information acquired from surveys of retired employees, IBM introduced retirement planning seminars to help employees develop plans to enhance their personal satisfaction in retirement. These seminars were originally designed for longer service employees, but they have proven to be valuable for employees of all ages since it is never too early to begin planning for the future.

3. Retirement Education Assistance Program (REAP) - Employees within five years of retirement eligibility and their spouses can receive tuition reimbursement (up to $2500 each) for courses completed which will help pursue new interests or develop a second career after retirement.

4. Community Service Career Program - Retirement-eligible candidates (retire from IBM with full retirement benefits) secure full-time paid positions in not-for-profit organizations, and receive a portion (35%) of their final IBM salary for two years. The receiving organization must commit two years of employment at a minimum of $10,000. (Candidates approved by management.)

5. Technical Academic Career Program - Retirement-eligible technical candidates retire from IBM with full retirement benefits, secure full-time paid positions in colleges and universities and receive a portion (35%) of their final IBM salary each year for two years. The receiving institution must commit two years of employment at a minimum of $15,000. These candidates are eligible for relocation assistance, if appropriate.

6. Pre-Retirement Leave of Absence - Allows employees who are retirement-eligible or within one year of retirement eligibility to take a one-year leave of absence without pay, but with full benefits. Individuals may work part-time during this period for IBM or for another employer where a conflict does not exist with IBM's business interests.

IBM Response to Employee Care Needs

In 1986 IBM conducted an Elder Care Feasibility Study in recognition of the aging demographics and their implication for our work force. The Corporation committed in 1987 to pioneering a national program to assist employees and retirees with their elder care responsibilities no matter where their elder relatives live.

In February 1988 IBM implemented the Elder Care Referral Service (ECRS). The service includes the following components:

- Personalized telephone consultation to help clarify the needs of the employee and the elder relative.
- Comprehensive development by a counselor, experienced, and trained in gerontology and elder care, of a range of options and alternatives for each specific case.
- Individualized referrals to possible sources of support that meet a family's preferences. This involves the counselor verifying basic information and availability of services when referrals are given.
- Written confirmation of referrals to services and elder care providers in a specific geographic area.
- Consumer education material to assist in selecting the most appropriate provider to meet specific needs, as well as information on financial and legal factors that should be considered in making a decision.
- Availability of the same elder care consultation specialist throughout the search process to answer questions or provide additional information.
- Follow-up contact two months after the service has been provided to determine if the employee's or retiree's needs are being met.

To date, over 13,000 IBMers have used the ECRS to find care for approximately 12,000 older relatives. Of those using the services, 72% are employees, 19% employee spouses, 9% retirees and retiree spouses. Many of the retirees are using the service for their parents.

The program that was developed for IBM has been made available to other corporations. To date, 11 other national employers have decided to offer the ECRS and currently 400,000 employees and their families are able to call for help.

Regarding older relatives, 52% of the calls involved long distance, caregiving situations where the older relative lived 100 miles or more from the caller. This reinforces our belief that this program minimizes employee distraction through the concept of "one-stop shopping" - saving the employee's time and enhancing IBM's productivity. The majority of older relatives (70%) are 75 to 89 years of age and 9% are age 90 or older. The program has been very successful, more than 85% of those who have used it have rated it helpful, which we consider high marks for the program.

An important part of the ECRS program design included some funds for resource development to help increase the supply of elder care services where shortages exist. This was to contribute to communities, and over time, better meet the needs of employees. With the help of ECRS Program Funds from IBM, more than 35 local resource development projects have been funded from February 1988 through December 1989. Proposals are submitted by local ECRS network organizations to our national contractor: Work/Family Directions. Projects are diverse and include:

- Volunteer respite care
- Expansion of home-delivered meals
- Shopping service
- Money management program
- Caregiver support claims
- Medicare claims assistance
- Nursing home visitation program

A breakdown of projects that have been funded is included in our information package.

The newest feature of the ECRS is the availability of an eight seminar series, "Caring for Elderly Relatives" in our A Plan for Life program. These seminars were designed to help employees anticipating, or already providing care for an older relative.

Our elder care programs enable our employees to solve the emotional dilemma of providing proper caregiving for their older relatives and help them develop a personal strategy for balancing work, family, self, and care-giving responsibilities.

New Initiative: IBM Elder Care Project Development Fund

On November 16, 1989, IBM announced new initiatives and enhancements of existing programs to provide additional support for employees to help them balance their work and personal life responsibilities. The key element of this announcement involves the creation of a $25 million fund available over the next five years to increase supply and enhance the quality of child care and elder care services in communities where IBM employees live and work. $22 million will be dedicated to child care issues and $3 million will be available for elder care programs and services. Financial support for specific projects will be distributed through the newly-established IBM Funds for Dependent Care Initiatives, which consist of two components: the IBM Child Care Resource and Development Fund and the IBM Elder Care Project Development Fund. These changes are intended to respond to IBM's business needs, as well as to build on our partnerships with employees and community organizations.

The IBM Elder Care Project Development Fund is intended to stimulate the development of new elder care services and, where possible, the expansion of existing services. This support represents an expansion of community projects already funded by the company.

Projects might include:

- o Respite care development.
- o Recruitment and training of in-home health and social service workers.
- o Intergenerational service programs.

Our new initiatives reflect our continuing effort to respond to our employees' needs and willingness to invest in our people in a financially responsible way. We believe that our menu of Work and Personal Life Balance Programs will enable us to attract and retain a motivated, dedicated work force, improve productivity, and ensure the long-term economic and competitive health of our business.

Ring-Ring — Pioneer Caregivers Calling!

For Ed, a 93-year-old retiree, taxi fare to his doctor's office used to cost $10 each way. That was until John began driving him to the appointments on his free time.

John is a "Pioneer Caregiver," a volunteer in an innovative support program run by retirees of the New Haven, Connecticut-based Southern New England Telecommunications Company (S.N.E.T). Under the year-old project, members of the Morris F. Tyler chapter of the 700,000 - strong Telephone Pioneers of America retiree service club visit other frail or convalescing members by telephone or in person, and help them with chores and errands.

The "Pioneers" as they are called, also visit retirees discharged from area hospitals. Both the Yale/New Haven Hospital and the Hospital of St. Raphaels identify SNET retirees on the basis of their insurance carrier and give them information on the caregiver program. Hospital administrators feel the program is a potential model for community linkages to discharge planning.

Cooperative Orientation

More than 45 retirees have been helped by the project, which involves 23 retired Pioneers. The volunteers are recruited through presentations at club meetings, formal letters, brochures, pension check stuffers and word-of-mouth. They attend a 10-hour orientation developed and administered by participating New Haven agencies and hospitals. Topics covered include special needs for frail or at-risk elderly, effective listening, and a guide to New Haven's services for older adults.

The orientation represents a cooperative effort, using staff and program models developed previously by the University of Connecticut, SAGE Services of Connecticut, the Trinity Parish of New Haven, the South Central Connecticut Area Agency on Aging, and two governmental agencies, the Senior Companionship Program and the Retired Senior Volunteer Project.

Company Support

S.N.E.T. funds a part-time project coordinator to work with community agencies, and donates office space for meetings and project administration.

.... members of the 700,000-strong Telephone Pioneers of America retiree service club visit other frail or convalescing members by telephone or in person....

In addition, retirees making telephone reassurance calls use a bank of phones specially installed by the company. Volunteers meet with the project coordinator on a regular basis to discuss suggestions for improving the program. For instance, the group quickly realized that maintaining confidentiality must be emphasized and reinforced due to the sensitive nature of caregivers' situations and those of the people that they are helping.

The motivation for the Caregivers Project stemmed partly from recognition by the company and retirees that, due to a reduction of company administrative and counseling staff, and the surge in number of retirees, the company no longer was able to provide a full range of support services.

The interest of S.N.E.T. in the project mirrors growing employer as well as general public policy concerns such as:

- The overall need for support services for frail and dependent older adults;
- The need to encourage new private involvement in long-term care;
- The value of developing meaningful new roles to enrich retired life;
- The promotion of community-based models for informal support for long-term care.

According to Jeanne Kardos, Director of Benefits at S.N.E.T., the Caregivers Project is a cornerstone to the company's interest in facilitating an employer response to the needs of older adults. "The next focus," says Kardos, "is to see how the company might help in developing a program of outreach to the parents of current company employees."

Robert Levin, Director, Institute on Aging, Work and Health of the Washington Business Group on Health.

OLDER AMERICANS PROGRAM

FACTS ON THE TRAVELERS CAREGIVING INITIATIVES

IN JUNE 1985 THE TRAVELERS CONDUCTED AN EMPLOYEE CAREGIVER SURVEY TO DETERMINE THE EXTENT OF CARE BEING PROVIDED BY EMPLOYEES TO ELDERLY RELATIVES. THE RESULTS INDICATED THAT:

* Twenty percent of all home office employees, age 30 and older, provide some form of care for an older person.
* These employees provide an average of 10 hours per week of care for an older person.
* For many, the demands of work and household, combined with caregiving responsibilities, are sometimes stressful.
* Eighty percent expressed a need for more information about community resources, insurance coverage and related issues.

THE TRAVELERS RESPONSE:

* A Caregiving Fair, which gathered more than 20 community agencies to provide information on a variety of topics including home health care, financial help and coping with stress. Approximately 700 employees and retirees attended.
* Lunchtime seminars on such topics as coping with psychological changes, housing options and intergenerational issues.
* A weekly support group in which caregivers share problems and ideas.
* Informational videotapes on caregiving.
* Articles on caregiving in the company newspapers.
* Caregiving reference section added to the corporate library.

OTHER ASSISTANCE TO CAREGIVERS:

* Flexible work time, in place since 1984, to facilitate caregiving employees' individual schedules.
* Dependent Care Allowance Program which automatically deposits pre-tax dollars from an employee's paycheck into a special account exclusively for dependent care expenses.
* Allowance of up to four weeks per year of unpaid personal leave.
* Employee Assistance Program that maintains three on-site counselors for assistance with personal and family matters.

The Travelers

The Travelers Companies
Hartford, CT 06183

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Your Travelers PASSPORT

PASSPORT NEWSLETTER: FAMILY CARE

Most of us have family members who depend on us in times of need. Sometimes these family needs – tending a sick parent or finding quality child care – can take up a lot of time and a lot of your paycheck.

To help with concerns about family care that can affect your personal and professional life, The Travelers is introducing a new Family Care benefit that offers:

- Paid and unpaid time off to care for family members who are ill.
- National information and referral service for locating child and elder care.
- A company subsidy to help with the cost of child and elder care.

In addition, the Dependent Care Spending Account (DCSA) will continue to offer a tax-advantaged way to pay dependent care expenses.

Time Off To Care

Sometimes you need a day off to stay home with a sick child; other times you may want months away from work to care for an infant or a convalescent parent. Family Care recognizes that these needs call for a new, formalized leave of absence policy.

- If you are a salaried employee, you can take up to three days off with pay during a calendar year when you need to care for a sick family member – as long as you have your supervisor's approval.
- After one year of continuous active employment, you can receive up to 12 months of unpaid leave when necessary to care for a child, spouse or parent. During this time, you can continue your Travelers medical, dental and life insurance coverage by contributing to the cost. If you return to work within six months, you will be given the same or a comparable job to the one you had before your leave began.

▼

OPENING

A WORLD

OF NEW

BENEFIT

OPPORTUNITIES

The Travelers

National Information And Referral Network

A new network will provide child and elder care information and referrals no matter where you work in the United States. On both a local and national level, referral counselors will be available to all employees. They can assist in the search for either child or elder care appropriate to your family's needs, including day care providers, nursing home or other custodial care facilities or home care services.

Financial Assistance For Family Care

Recognizing how important and expensive quality dependent care is, The Travelers will offer financial assistance to help pay for dependent care. If you have opened a DCSA, The Travelers will reimburse a certain portion of your eligible expenses, based on your annual pay. A summary of Family Care benefits is shown below.

Family Care At A Glance

Your Annual Pay	% of Expenses Reimbursed	Maximum Annual Benefit
Less than $20,000	30%	$1,200
$20,000 to $29,999	20%	$ 800
$30,000 to $39,999	15%	$ 600
$40,000 or more	10%	$ 400

For example, if you earn $19,000, The Travelers will pay 30% of your eligible expenses, up to a maximum of $1,200 per year.

You must open a DCSA to receive Family Care benefits. Funding this benefit through a DCSA allows The Travelers to provide this subsidy without being taxable to you. Any expenses that are eligible for reimbursement through your DCSA will qualify for reimbursement by The Travelers.

Dependent Care Spending Account (DCSA)

A DCSA lets you set aside part of your gross pay–before federal income and Social Security taxes are withheld from it–to pay for qualified dependent care expenses. The money you normally pay in taxes on your DCSA deposits goes into your pocket instead, and you are actually buying necessary child or elder care with money that isn't taxed.

To be eligible for DCSA reimbursement, dependent care expenses must allow you and your spouse to work, look for work, or attend school full-time. This includes the cost of:

- Pre-school care for children under age 6;
- Before- and after-school care for children between ages 6 and 13, and;
- Care for a dependent of any age who is mentally or physically disabled, claimed as a deduction on your income tax return, and spends at least eight hours a day in your home.

The most you can contribute to your DCSA by law is $5,000. This maximum is reduced by the amount that The Travelers pays in Family Care benefits. For example, if you earn $22,000 and expected to receive $800 in Family Care benefits, the maximum you can contribute to your DCSA would be $4,200 ($5,000 – $800).

Under certain circumstances, federal regulations may further limit your DCSA contributions. Your enrollment guide will contain more guidance on DCSA, as well as a more detailed list of the eligible dependent care expenses.

Example

Here is an example of how using Family Care benefits and DCSA can work together to help you with your dependent care expenses. Consider Lisa and her husband Mike. They both earn $24,000 a year, they file a joint return and claim three exemptions. They estimate that during the next year they will have $5,000 in eligible dependent care expenses for their infant son.

As a Travelers employee, Lisa is eligible for Family Care benefits. She qualifies for the maximum benefit of $800, based on her income of $24,000. This leaves eligible expenses of $4,200 ($5,000 – $800) which she can pay through her DCSA. This will reduce the couple's taxable income, so they pay lower federal income and Social Security taxes and increase their spendable pay. If they also pay state income taxes, using the DCSA would further increase their disposable income.

Example of DCSA

	No DCSA	With DCSA	Difference
■ Joint income	$48,000	$48,000	
■ Dependent Care Account	–	−4,200	
■ Taxable income	$48,000	$43,800	
■ Federal income and Social Security taxes*	−9,380	−8,520	−$1,360
■ After-tax pay	$38,120	$35,280	
■ After-tax dependent care expenses	−5,000	–	
■ Spendable pay	$33,120	$35,280	+$2,160

*Based on 1989 tax rates.

Lis[illegible]d Mike save $1,360 in taxes by paying these expenses through the DCSA. If you add to this the $800 they receive in Family Care benefits, they end up with $2,160 more in spendable pay than they would if they paid their dependent care expenses on an after-tax basis.

■ ■ ■

Dependent care is becoming more difficult to locate and afford. Family Care is an innovative response to today's issue of dependent care. Paid and unpaid time off can help relieve the pressure of balancing personal and professional obligations when you need time off to care. Information and referral services can help you find quality child and elder care. The Traveler's Family Care subsidy – combined with the tax advantages of DCSA – can help make dependent care more affordable.